

For Parents:

Your pituitary infant, birth to 5 years



The Pituitary Foundation Information Booklets

The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families

About this booklet

The aim of this booklet is to provide information for parents who have a baby or young child with a pituitary condition. You may find that not all of the information applies to your child in particular, but we hope it helps you to understand the condition better, and offers you a basis for discussion with your child's GP and their paediatric endocrinologist.

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The impact on parents

Becoming a parent, or having a toddler, can be hard work amidst a lot of joy. The additional responsibility of having to manage your child's pituitary condition could be quite overwhelming. Parents have to learn pretty quickly how to deal with medication doses, any symptoms that arise, and how to seek help.

As your young child develops, new issues arise such as immunisations, childhood illnesses and intercurrent infections, for which medication doses may need to be changed. Starting nursery/school brings its own concerns regarding your child's safety, growing up, being different in class, and exposure to infections.

Once you find a diagnosis for your child, it is probably a relief to find a reason for his/her symptoms. However, you may feel too shocked and numb to take in what you were told initially. As the shock wears off, you begin the coping process. At first, you may deny anything is different. Once you accept that your

child has a life-long condition, you may feel many emotions such as anger, guilt, or sadness. Relationships within the family might be altered, and sometimes strained, as everybody adjusts to the situation. Sometimes, other children in the family get a lot less time and attention. All of these are not unusual. With time and understanding of your child's condition, coping as a family becomes less stressful.

Taking care of yourself

As a parent, you need to look after yourself in order to care for your child, as well as the rest of your family. Make sure that you are getting enough rest, healthy food, and exercise. Find people that you can talk to about how you feel, as it can help to speak with someone who understands. You may want to join a support group or be put in touch with other parents to talk with who have a child with a similar condition. *See the 'Support for you' section on page 13.*



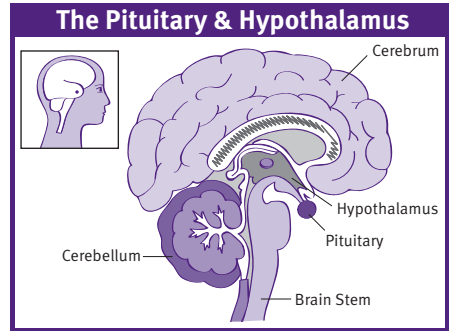
What is the pituitary gland and what does it do?

The pituitary gland is about the size of a pea and is situated in a bony hollow, just behind the bridge of the nose. It is attached to the base of the brain by a thin stalk. The hypothalamus, which controls the pituitary by sending messages, is situated immediately above the pituitary gland.

The pituitary gland is often called the master gland because it controls several other hormone glands in the body, including the thyroid, adrenals and ovaries or testicles. It secretes hormones from both the front part (anterior) and the back part (posterior) of the gland. Hormones are chemicals that carry messages from one cell to another through the bloodstream. Hormones are important for growth, puberty, energy levels and day-to-day normal life. If the pituitary gland is not producing sufficient amounts of one or more hormones, this is called hypopituitarism. Occasionally, too much hormone may also be produced.

The hypothalamus

The hypothalamus serves as a communications centre for the pituitary gland, by sending messages or signals to the pituitary in the form of hormones, which travel via the bloodstream and nerves down the pituitary stalk. These signals, in turn, control the production and release of further hormones from the pituitary gland, which signal other glands and organs in the body. The hypothalamus also influences temperature regulation, food and water intake, sleep and wake patterns.



What causes babies and young children's pituitary conditions?

Underactivity of the pituitary gland or hypopituitarism may result from several different causes. There may be a congenital (present from birth) abnormality in the formation of the gland. Sometimes hypopituitarism is due to a slow-growing tumour called a craniopharyngioma, in the brain above the gland.

Various diseases may damage the gland and cause hypopituitarism. Pituitary problems can occur after a severe head injury or as a side-effect of treatment with radiotherapy to the head, which may be needed for brain tumours. Infection in the brain can also result in hypopituitarism.

A number of genetic causes have now been found to cause hypopituitarism in children. Many of these genes are important to help develop the pituitary gland when your child is in the womb. The eye nerves and pituitary develop together in early life; sometimes if the process is faulty, hypopituitarism occurs in association with problems with vision in one or both eyes. This is called septo-optic dysplasia.

Diagnosis



The Foundation recommends that referral is made to a paediatric endocrinologist in a centre of excellence, for testing and diagnosis of pituitary problems. A centre of excellence will have the expertise and experience of managing pituitary conditions in babies and young children, by a multi-disciplinary team (MDT).

Diagnosis depends on the measurement of pituitary hormones in the blood, either as a one-off, or after stimulation tests over several hours to show more clearly how the gland works. Scanning of the head, usually with an MRI (magnetic resonance imaging) scan can show the structure of the gland and surrounding structures. An assessment of your child's eyes may be needed by an ophthalmologist.

Treatment and ongoing care

Treatment consists of replacing either the missing pituitary hormones themselves, or of the hormones produced by the target glands. The

most important of these hormones are:

Hydrocortisone replaces the stress hormone cortisol, produced from the adrenal glands. Cortisol is important in maintaining blood sugar levels and protecting against stress and illness such as infection. Current replacement of hydrocortisone is by tablets, which are taken in split doses several times daily, as advised by your child's paediatric endocrinologist. Hydrocortisone tablets are usually provided as 10 mg tablets; a tablet

may need to be cut into smaller pieces to give a smaller dose. For example, a dose of 2.5 mg is a quarter of a 10mg tablet. In young children who are not able to swallow tablets, hydrocortisone may be dissolved in a small amount of water at room temperature and then swallowed. Your doctor will advise you on the dose and how many times to give in a day.

There is a new form of hydrocortisone which presents as granules in capsules for opening. Hydrocortisone granules are available in 0.5 mg, 1 mg, 2 mg and 5 mg capsules which may offer more precise dosing

You'll be given 'sick day rules' information in the event your child needs increased hydrocortisone or an injection in emergency situations. Please see pages 8-11 for sick day rules and our **Hydrocortisone Advice leaflet for parents** at www.pituitary.org.uk/information/publications/essential-free-publications/hydrocortisone-advice-for-parents-leaflet/

Levothyroxine is the replacement for thyroxine which is made by the thyroid gland. Thyroxine is a hormone which is critical to brain development in early life, and also helps with several bodily functions including growth. Levothyroxine is usually in the form of tablets which are taken early morning, half an hour before breakfast. A liquid preparation of levothyroxine is also available. The dose of levothyroxine will vary according to need and will be instructed by your child's paediatric endocrinologist.

Desmopressin (DDAVP) is the replacement treatment for anti-diuretic hormone (ADH) which is produced in the back part of the pituitary gland. This hormone circulates in the bloodstream and acts on the kidneys to control the amount of water passed out of the body as urine. If ADH is deficient, it will cause the condition called diabetes insipidus (water diabetes). Desmopressin is given usually two to three times a day by tablets that need to be swallowed, tablets that melt in the mouth and nasal sprays.

Recombinant human growth hormone (GH) is the replacement treatment for growth hormone that is responsible for growth throughout childhood. Replacement consists of single injections under the skin every day. Most growth hormone devices are needle devices which deliver a small dose of the treatment through a small sharp needle. A needle free device is also available.

Sex hormones: testosterone in boys, and oestrogen in girls, may be needed later on to help children with hypopituitarism to progress in

puberty and to maintain sexual development in adults. Replacements are available in the form of gels, tablets, creams, patches and injections. Our new booklet in this series called **For Parents: Your pituitary child, 5 to 11 years'** explains more about puberty

Hormone deficiencies in hypopituitarism can be very variable. In some children, only GH needs to be replaced, whereas in others, all the hormones need to be replaced. In some children, puberty can be late if the puberty hormones are deficient. In children with septo-optic dysplasia and children who have been treated with radiotherapy, puberty may develop early. Once growth is complete, adolescents are usually re-tested to check if they have growth hormone deficiency as young adults. In young adults with growth hormone deficiency, growth hormone is not required for growth but is used at lower doses for its beneficial effects on body composition and bone mineral density.

Monitoring your child at clinic

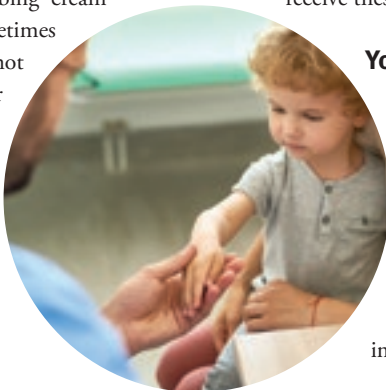
In the early days, appointments with your child's paediatric endocrinology team could happen fairly often, and once your child is more stable, these could occur at three, or six monthly intervals.

At your first clinic appointment clinic, you and your child will normally see a consultant. If you are seen by a junior doctor first, a consultant will always review and discuss your child's condition and care. First appointments usually last between 20 and 40 minutes.

At the clinic, they will carry out a number

of assessments and tests to help them build a picture of your child's growth and development. They will usually measure your child's height and they may measure the parents' heights too.

They may take blood and urine samples or carry out x-rays. All of these tests are usually carried out on the same day as your clinic appointment. If they take a blood sample, your child would be given a 'numbing' cream or spray to reduce pain. Sometimes one-off blood samples are not adequate to find out if your child's pituitary hormones are deficient. In that case, your child may need a stimulation test, also called a dynamic function test, which may last for up to three hours.



After your appointment

After your child's appointment, a letter will be sent to your GP or the doctor who referred you to the clinic. A copy of the letter will also be sent to you and any other doctors and health professionals involved in your child's care. The letter will contain contact details in case you have any questions. If your child needs a follow-up appointment, this will be arranged before you leave the clinic.

Questions to ask the paediatric endocrine team

- What should I watch out for and what do I do if it happens?

- How do I contact the ward or department?
- Is there a fast access to medical help if my child is unwell – what is this?
- Medicines my child needs; how does she/he take these
- Repeat prescriptions, does my GP provide these?
- Future outpatient appointments – will I receive these by post?

Your child's file

It can help if you store all the information about your child in one place. This makes it easier to find key pieces of information and share them with your child's health care team, GP and at home. Suggestions to include in this file:

- Track changes in your child's treatment and their height and weight
- Note contact details for everyone involved in your child's care
- Prepare for appointments and admissions
- Write down any questions and answers
- File copies of clinic letters and leaflets
- Emergency details
- Provide information to other people looking after your child, such as grandparents, relatives, childminders, and nursery.

Sick day rules

When to increase a child's hydrocortisone dose

If a child with cortisol deficiency becomes unwell due to another illness, he/she is unable to increase the production of cortisol, which is needed to help the body cope with the illness.

In these circumstances, the amount of hydrocortisone given needs to be increased to mimic the body's normal extra hormone production in time of need. In most cases, the usual hydrocortisone is doubled and given 4 times a day for 2 days. If your child is very unwell and is unable to keep food or fluids down, then it is best to give an intramuscular dose of hydrocortisone. Your specialist nurse will teach you how to do this. Emergency intramuscular hydrocortisone injections can be life-saving.

You may wonder when to give double dose hydrocortisone, especially if your child is well with minor viral infections such as coughs and colds. As a parent, you will be able to judge if your child is more ill than usual with the illness. It is worth noting that an extra dose will not do any harm. **So, if in doubt it is better to give the additional hydrocortisone than not. The same also applies for intramuscular hydrocortisone.** If your child is unwell enough to require double dosing of hydrocortisone, ensure that the morning doubled dose is given early morning and is not delayed. If your child has been given a hydrocortisone injection, he/she must be admitted to hospital afterwards to be monitored. The monitoring should be for 12 hours or longer. This is because the effects of the injection only last about 6 to 8 hours, and it is

important to check that the child is stable on oral dose before going home.

Diarrhoea and/or vomiting

It is important not to ignore diarrhoea and/or vomiting, especially if your child is also taking tablets such as desmopressin (DDAVP). Diarrhoea and/or vomiting can cause your child to become dehydrated with imbalance of salt and water levels in the body.



Coughs and colds

If the child has a minor head cold with snuffles, runny nose and a cough but is otherwise well, there is usually no need to increase the oral hydrocortisone. However, if you feel your child is more lethargic than usual, there is no harm in giving hydrocortisone as per sick day rules.

Temperatures

If your child has a raised temperature (fever), he or she may require hydrocortisone as per sick

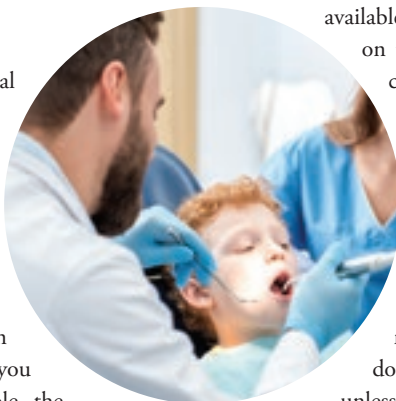
day rules. However, if your child is well despite fever, you may wish to give him/her usual dose hydrocortisone.

Antibiotics

If your child has been prescribed antibiotics for an infection, e.g. a chest infection, tonsillitis or middle ear infection, it is best to give hydrocortisone as per sick day rules. In most cases, double dose hydrocortisone is required for two days, but if the infection persists, you may give double dose until the infection resolves. Please note that for chest infections, the cough may last for more than a few days. It is not necessary to give double dose hydrocortisone for the duration of the cough.

Dentists

- If your child has a dental appointment for a check-up or cleaning, he/she should not need any extra hydrocortisone.
- If your child has an appointment for fillings or other treatments which require a pain relieving injection, you should give them double the dose of oral hydrocortisone for the 24-hour period around the appointment.
- If your child unexpectedly needs an injection for filling or other treatment for broken teeth for example, give them double the dose of oral hydrocortisone as soon as possible, and



continue for the next 24 hours.

- Major dental work, such as having teeth removed, should only be carried out in hospital. Please call your specialist treatment centre for advice before the appointment. If your child is being put to sleep (general anaesthesia) for teeth extraction, your paediatric endocrinology team will advise the surgical team to give additional intravenous hydrocortisone as per local protocol.

General anaesthesia

If your child needs general anaesthesia for any reason, extra hydrocortisone given intravenously (IV) will be needed as they go to sleep. The endocrine team your child sees would be available to advise your local hospital on the dose needed and can be contacted.

Your child could have an alert attached to his/her file to remind staff that he/she is on hydrocortisone.

It is still important to remind staff in all centres that your child needs medication regularly and that doses should not be omitted unless hydrocortisone is given intravenously.

Immunisations for childhood illnesses

Immunisations are not contraindicated while on replacement hydrocortisone therapy. All children on hydrocortisone are encouraged to

complete all routine immunisations.

If your child is taking medications other than hydrocortisone, you should ask your specialist treatment centre for advice.

After the injection of immunisation, you may consider giving double dose hydrocortisone, particularly if your child is distressed or in pain. Some children develop a fever and rash a few days after the injection. You should follow the advice under 'temperature' if this happens. If your child is well after the injection, you may continue usual dose hydrocortisone.



Accidents and injuries

If your child has a fall, bump or bruise, but immediately recovers and carries on as normal, there is no need to give double dose

hydrocortisone. If you are worried, it is best to contact your specialist treatment centre.

However, if your child has a serious injury, for example, bumps his/her head and becomes unresponsive and unconscious, then you will need to give them an intramuscular injection of hydrocortisone and call an ambulance to take them to hospital immediately. In hospital, alert staff attending to your child that he/she has hydrocortisone and that you had given him/her an intramuscular dose of hydrocortisone at home.

Unresponsive child/hypoglycaemia

If your child runs short of cortisol, he/she may have low blood sugar levels (hypoglycaemia). The signs of hypoglycaemia are:

- pale
- sweaty
- drowsy
- confused
- eyes appear glazed
- not responding

If you think your child has hypoglycaemia, you should give your child an intramuscular injection of hydrocortisone and call an ambulance to take him/her to hospital immediately. While waiting for the ambulance, if your child is conscious, give him/her glucose gel that you should have in your emergency pack. Give this by squirting the gel in the mouth between the gums and the inside of the cheek. If your child is unconscious, do not give him/her anything to eat or drink, including glucose gel.

Special note for children with diabetes insipidus who are taking desmopressin (DDAVP)

If your child needs extra oral hydrocortisone for vomiting and/or diarrhoea:

- Do not give them any more DDAVP
- Allow them to drink if thirsty
- Ensure that your child is passing urine
- If passing less urine or vomiting, you should consider taking your child to hospital.
- If vomiting and not keeping down medication, give an intramuscular injection of hydrocortisone



Emergency kits

Your specialist treatment centre will give you an emergency medication kit, which should be with your child at all times. You may ask for more than one kit to be kept elsewhere, for example at school. Emergency kits have a one year expiry date; do check from time-to-time if your kits and medication supplies are in date. It is a good idea to video your emergency injection training session by the endocrine team, on your phone as a refresher for any future need.

Each kit should contain:

- 1 x vial of 100mg/1ml of hydrocortisone for intravenous/intramuscular injection. Some preparations require reconstitution using water for injection
- A filter needle for glass ampule
- 1 x 2ml syringe
- 2 x blue needles (or orange needles, depending on age)
- 1 x tube of glucose gel with instructions for use
- 1 x leaflet 'How to give an emergency injection of hydrocortisone'
- 1 x steroid card filled in with child's details.

Emergency injections

letter about your condition, your medication and your doses prescribed. This letter will be helpful should you become unwell and have to see a doctor. It is also useful for you to have this letter while going through airport security, in the event that they question your medication. If you have a repeat copy prescription this can also be shown.

It is suggested that you have a 100mg injection kit while you are travelling abroad, in case of emergency. If you are to travel to an area where your emergency injection kit may be subject to sustained temperatures exceeding 25°C, then it should be placed in a small cool bag. All of your medication should be labelled with your name and kept with you at all times during your journey, as part of your hand luggage.

At check-in they will ask if you are carrying anything sharp i.e. needles; please mention if you are carrying injection needles for your medical condition.

It is wise to take an extra two weeks supply of hydrocortisone tablets with you in case you need to increase your usual dose whilst away.

How to give an emergency injection of hydrocortisone

Powder version: SOLU-CORTEF



1. Wash and dry your hands.
Snap open the sterile water - use a small piece of tissue to protect your fingers.
Attach the green needle, to the syringe and remove the cover. Withdraw 2ml of sterile water into the syringe.



2. Remove the cap off the vial of hydrocortisone powder. Inject the water into the vial of powder.



3. Swirl the vial until all the powder is mixed with the water. Withdraw the contents of the vial into the syringe.



6 Hydrocortisone advice

Practical advice

Signposting hydrocortisone use

All children on steroid replacement therapy should carry some identification stating cortisol insufficiency. This could be by wearing a medical identity bracelet or necklace. One alternative is to keep a steroid card stating information about hydrocortisone dosage. Another alternative is to store the health data in your mobile phone (or your child's if he/she has one when older). Further information about these can be obtained from the paediatric endocrine specialist nurses.

App for your mobile phone

My Cortisol is a free app available for Android and Apple devices to help with emergency care of children with cortisol deficiency.

Travel

When travelling there are a few things to consider:

Book in the child's travel vaccines with the GP and follow the immunisations advice as necessary. Discuss your travel programme with your paediatric endocrine specialist nurses. If travelling abroad, you will need a customs letter (or letter from your paediatric endocrinologist for travel). You will need to carry your emergency kit on board a plane. Your customs letter will state that your hand luggage will contain sharps, needles and fluids. You may have to take more than 100 ml that is normally allowed. Ensure there is enough medication for the holiday, including doses of hydrocortisone for the entire duration of your stay. When changing time

zones, it is safest to give the normal morning dose then repeat eight-hourly (if on three times a day) or six-hourly (if on four times a day) until the morning of your destination's time zone and then commence at normal times and doses from that point.

- If your child is also on DDAVP please call the paediatric endocrine specialist nurses team for advice.
- Ensure your travel insurance company is aware of your child's cortisol deficiency as this will need to be registered as a pre-existing condition.
- Find out how to contact an ambulance and where the local hospital is located near your destination before you travel. If your child is unwell, you do not want to be finding out this information at that point.

Nursery and pre-school

If your young child is starting nursery or pre-school and takes steroids, and/or desmopressin, you should ensure there is a treatment plan which is discussed with the staff involved in your child's care.

The treatment plan should include your child's condition, medications taken, emergency contact numbers, and guidelines in the event your child becomes unwell and needs prompt medical attention. Our **Care Guide for schools** is a template for you to complete and is available here www.pituitary.org.uk/information/publications/essential-free-publications/hydrocortisone-care-guide-for-schools/

Support for you

Our website has a section of information and signposting for parents here www.pituitary.org.uk/support-for-you/carers-and-parents/

The Pituitary Foundation has a group specifically supporting younger patients and their parents, and the group covers the UK. Our informal support groups differ from other local support groups in that they mainly have an online presence and offer telephone support instead of regular face-to-face meetings as they are not location specific. The four Co-ordinators of the group are Richard Jackman and George Marriott, and their mothers Alice Jackman and Rachel Marriott. They are there to offer peer support and information so do please get in touch.

Occasionally, the younger people's group represents The Pituitary Foundation at events where the subject of younger pituitary patients is

prominent. The group also helps run the sessions for younger people at Pituitary Foundation Conferences. The co-ordinators also help The Foundation to maintain and keep up to date our support information for younger patients.

We also have informal support offered from other parents with younger children and please contact us if you want to be put in touch with them, via helpline@pituitary.org.uk

Useful links

Contact (family support)

Freephone: 0808 808 3555

9.30am-5pm, Monday-Friday; free from UK landlines and UK mobiles

www.contact.org.uk

Turn 2 us (Benefits advice etc.)

www.turn2us.org.uk



A parent's story

Jack was born with the condition congenital hypopituitarism. He was induced at birth, as I had been monitored in the John Radcliffe hospital in Oxford, due to kidney issues when I was younger.

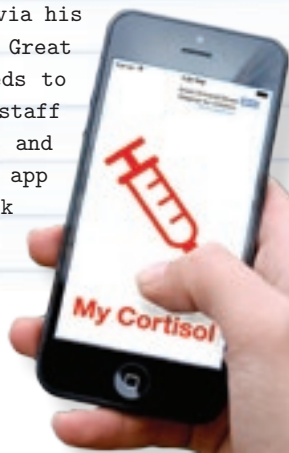
Jack was very pale, very lethargic and cold when he was born and spent his first two weeks in special care. He was not feeding well and was jaundiced and had no energy. His genitals were very tiny, even for a baby.

After a brain scan in his first weeks, and constant blood tests and monitoring, they diagnosed his condition and confirmed that his pituitary gland had not formed properly.

Jack had to start taking hydrocortisone - a replacement tablet for cortisol which he didn't produce naturally due to his faulty pituitary gland. We had to crush the tablets and put them in his milk, ensuring that every last drop was taken. Levothyroxine tablets were introduced later and again these would be crushed and placed in drinks.

We are very lucky as we have a wonderful endocrine team at the John Radcliffe who know Jack and have given us great support these past 15 years. We can phone the paediatric on call and request assistance if we are unsure how to manage illness. We have good contact with the paediatric endocrine nurse and consultant, who we can contact if we think things may be changing with medication needs etc. Jack attends hospital every six months for check-ups.

Jack and I have an app on our phones provided via his paediatric endocrine nurse. It was produced by Great Ormond Street hospital and means that if he needs to get into hospital that you can give the phone to staff and it tells them that he is cortisol dependant and what they need to do should he be admitted. The app is called "My Cortisol" and also includes a quick link to call an ambulance.



Please support The Pituitary Foundation

Join the The Pituitary Foundation today and enjoy the benefits of membership!

- ✓ Receive our members' magazine, *Pituitary Life*, three times a year full of the latest information, updates and patient stories, to help you better understand, or manage your pituitary condition.
- ✓ Our monthly e-bulletin, which includes the latest pituitary news, information and ways to get involved.
- ✓ Become an important part of the only charity in the UK providing support to pituitary patients.
- ✓ Receive a welcome pack and a membership card and enjoy discounts to Pituitary Foundation events, such as our conferences.
- ✓ Give us a stronger voice to raise awareness, and understanding, of pituitary disorders.

Individual membership costs **£25.00** for a full year, which is only **£2.08** a month!

(Family, concessionary and life membership rates are also available). To become a member, please complete the form below and return to us with your payment (cheques made payable to **The Pituitary Foundation**) to:

The Pituitary Foundation,
86 Colston Street,
Bristol, BS1 5BB

If you would like to pay for your membership by standing order, please contact **0117 370 1333** or to join online visit **www.pituitary.org.uk**

I wish to become a Member of THE PITUITARY FOUNDATION			
Title:	First Name:	Surname:	
Home Address:			
Postcode:			
Telephone No:	Email:		
Please tick (✓) the type of Membership you require:			
Individual	<input type="checkbox"/> £25.00 (annual)	Joint	<input type="checkbox"/> £35.00 (annual)
Life Membership	<input type="checkbox"/> £350.00	Concessionary*	<input type="checkbox"/> £15.00 (annual)
Additional donation (optional) £			
<i>*(Concessionary rate for people on a state pension, in receipt of state benefits, on low income, students, and under 18s only).</i>			
<input type="checkbox"/> Yes! I want to Gift Aid any donations I have made in the past, present and future to The Pituitary Foundation. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify The Foundation if you want to cancel this declaration, change your name or full address, or no longer pay sufficient tax on your Income or Capital Gains.			
Signature:	Date:		

Helpline

Monday - Friday 10:00am-4:00pm
0117 370 1320

Endocrine Nurse Helpline

available scheduled hours
0117 370 1317

Website: www.pituitary.org.uk

Email: helpline@pituitary.org.uk

More Information

The Pituitary Foundation publishes a library of booklets on pituitary conditions, treatments and well-being issues.

For more information please visit our website, or call our Helpline.

The Pituitary Foundation

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Disclaimer: All information is general. If you or your carer, have any concern about your treatment or any side effects please read the Patient Information booklet enclosed with your medication or consult your GP or endocrinologist.

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The
Pituitary
FOUNDATION

Working to support pituitary patients, their carers & families