

Pegvisomant

Information for patients

This leaflet is about Pegvisomant treatment. It explains why you might need this treatment, the benefits and risks, and what to expect on your visits to hospital. If you have any queries or concerns, please speak to the doctors or nurses caring for you.

What is Pegvisomant?

Acromegaly is a condition caused by an excess growth hormone from a pituitary tumour. Current treatment with surgery and radiotherapy is effective but does not work for a small number of patients. Current medical treatment with somatostatin analogues is effective in about half of patients.

Pegvisomant (Somavert) blocks the effect of growth hormone at the receptor. This reduces the level of IGF-1 (insulin like growth factor-1, which is the primary mediator of growth hormone action), and controls acromegaly.

Why do I need this treatment?

Pegvisomant helps manage uncontrolled acromegaly after pituitary surgery or radiotherapy. It works by normalising growth hormone effects in the body and controlling symptoms caused by persistent growth hormone secretion.

It reduces serum IGF-1 levels into the normal range.

What are the benefits of Pegvisomant?

It has shown to achieve almost full biochemical control in patients, and is very well tolerated.

What are the side effects of Pegvisomant?

Less than 5% of side effects are injection site reactions. The most common side effects are:

- sweating (7%)
- headaches (6%)
- asthenia (abnormal muscle weakness or lack of energy) (6%)
- temporary elevation of liver levels

Are there any alternatives?

There are no alternatives to this treatment.

What happens before my treatment?

The pituitary multidisciplinary team (MDT) needs to agree that you need and would benefit from this treatment. You will then be seen by your Consultant Endocrinologist or nurse specialist to talk about starting you on this medication and ensure you are happy to start the treatment.

A form will be completed by a Consultant Endocrinologist before a prescription can be requested.

Pegvisomant is considered to be a third line treatment for patients who have already had surgical intervention or radiotherapy with persistent, active acromegaly with at least two of these factors:

- clinical symptoms or active complications of acromegaly
- elevated age-related IGF-1 level
- elevated mean GH (less than 5Mu/l) after a standard growth hormone test or oral glucose tolerance test

What happens during my treatment?

We will invite you to the hospital endocrine unit (Programmed Investigation unit) to start a loading dose Pegvisomant injection. We will give you training on how to self-administer the injections at home.

Your specialist nurse will register you for homecare delivery supply for your daily injections.

How do I take Pegvisomant?

Pegvisomant is given via injection subcutaneously (under the skin fatty tissues) and given daily. You will be started on low dose of 10 to 20mg daily as recommended by your Endocrinologist.

The dosage may be adjusted based on your blood tests. This will be decided and reviewed by your Consultant Endocrinologist.

What happens after my treatment?

You will have a follow-up blood check within 1 to 3 months in the first 6 months to monitor your routine IGF-1 levels, liver function tests, and any adverse effects of treatment such as gastrointestinal symptoms, headaches and fatigue.

The Pituitary multidisciplinary team will discuss your care in a team meeting and if there is evidence that you are responding well on this treatment then you will be advised to continue the medication long-term.

Further information

The below websites give further information about Pegvisomant:

Pfizer:

www.pfizer.com/products/product-detail/somavert

National Institute for Health and Care Excellence (NICE):

Contact details

If you have any clinical queries, please contact endocrine nurse specialists:

Leah Laniba and Nadia Gordon on **020 3299 4047** or **020 3299 2047**.

Email: kch-tr.endonurses@nhs.net

Available Monday to Friday 9am to 5pm.

Consent

We must by law obtain your written consent to any operation and some other procedures beforehand. Staff will explain the risks, benefits and alternatives before they ask you to sign a consent form. If you are unsure of any aspect of the treatment proposed, please do not hesitate to speak with a senior member of the staff again.

Sharing your information

We have teamed up with Guy's and St Thomas' Hospitals in a partnership known as King's Health Partners Academic Health Sciences Centre. We are working together to give our patients the best possible care, so you might find we invite you for appointments at Guy's or St Thomas'. To make sure everyone you meet always has the most up-to-date information about your health, we may share information about you between the hospitals.

Care provided by students

We provide clinical training where our students get practical experience by treating patients. Please tell your doctor or nurse if you do not want students to be involved in your care. Your treatment will not be affected by your decision.

PALS

The Patient Advice and Liaison Service (PALS) is a service that offers support, information and assistance to patients, relatives and visitors. They can also provide help and advice if you have a concern or complaint that staff have not been able to resolve for you. The PALS office is located on the ground floor of the Hambleton Wing, near the main entrance on Bessemer Road - staff will be happy to direct you.

PALS at King's College Hospital, Denmark Hill, London SE5 9RS

Tel: 020 3299 3601

Email: kch-tr.palsdh@nhs.net

You can also contact us by using our online form at www.kch.nhs.uk/contact/pals

If you would like the information in this leaflet in a different language or format, please contact PALS on 020 3299 1844.