

Growth hormone therapy in PWS UK practice



Introduction

Growth Hormone (GH) therapy is recommended for growth failure in children with Prader-Willi Syndrome (PWS) – this is supported by the National Institute of Health & Clinical Excellence (NICE) and this guidance is published as ‘Technology Appraisal 188’ by NICE.

The published guidance can be found at <https://www.nice.org.uk/guidance/TA188>
The guidance also suggests that response to GH therapy in PWS children should also consider body composition (and not just growth promotion).

How to obtain GH therapy for your child

GH therapy is always initiated and monitored by a specialist – generally a paediatric endocrinologist or paediatrician with expertise in growth disorders. However, the actual steps involved in this process can widely vary between different regions and hospitals. GPs generally do not initiate treatment, although in many areas they do prescribe the GH on the instructions of the specialist.

The generic process is as follows:

- Specialist with expertise – generally based at the hospital, decides when to start GH for a child with PWS. Specific tests to prove GH deficiency is not required, but it is essential to prove the diagnosis of PWS by genetic analysis.
- There are a number of GH preparations licensed for use in UK. The family decides which GH preparation to use based on their own personal preferences and the devices available to administer GH – the specialist provides information to the family (and the patient, if appropriate) and guides them in making their own choice.

Continued ...

Getting NHS funding

Although there appears to be a hugely confusing and long winded procedure to follow sometimes, almost all children with PWS have successfully received NHS funding following the specialists’ decision to start GH therapy.

The NICE recommendations (revised in 2010) confirm that all children with genetic confirmation of PWS and with growth failure and/or deranged body composition are eligible to receive NHS funding for GH therapy in the future too.

How to obtain GH therapy for your child (continued)

- Following the specialist's decision to start GH therapy and patients choice of the GH preparation, the specialist organises training to the parents and if appropriate to the patient in the home administration of GH. The training is usually provided by the specialist nurse who works with the specialist. Sometimes the training is provided by an external agency or by the GH company itself.
- The specialist also informs the local commissioning group or another subdivision (like the pharmacy committee etc.), seeking approval for the costs of GH therapy. Depending on the local processes, the specialist or the patient's usual GP provides the prescriptions for GH on a regular basis. Some GH companies also provide additional facilities like collection of the GH prescription from the hospital or surgery and direct home delivery of the GH.
- The actual steps involved in this process can vary widely. In addition, the NHS itself is undergoing a major restructuring including the process of commissioning; hence some of these steps are bound to change when new systems come into practice.
- The specialist who initiates the growth hormone, will consider and organise various tests prior to the start of GH; also regular tests after starting GH to monitor the dose and safety of continued GH treatment for the patient.

Acknowledgement

Thank you very much to Dr Shankar Kanumakala, Consultant Paediatrician, Royal Alexandra Children's Hospital, Brighton for contributing this article.

PWSA UK

Suite 4.4 , Litchurch Plaza
Litchurch Lane
Derby DE24 8AA

T: 01332 365676
E: admin@pwsa.co.uk
W: www.pwsa.co.uk

Reg Charity No: 1155846
© PWSA UK