Laronidase (Aldurazyme®)

Please disseminate the following information to the appropriate individuals within your organisation across NHS Wales.

Dear Colleague,

The Minister for Health and Social Services has endorsed AWMSG's recommendation to support the use of laronidase within NHS Wales. It has been agreed that:

AWMSG would support the use of laronidase (Aldurazyme®) within NHS Wales subject to the following restrictions:-

1. Use of laronidase will be in accordance with:-

    (a) the drug's Summary of Product Characteristics (SPC), subject to paragraph 2 below; and
    (b) agreed uniform service standards and clinical guidelines;

2. AWMSG recognises that some current uses of laronidase fall outside the drug's SPC (such as its short term use before and after Bone Marrow Transplantation). Any use which falls outside the SPC will only be supported if part of an approved clinical trial.

Patients from Wales will be treated at either:-

(a) the specialist centre for the treatment of lysosomal storage disorders at the University Hospital of Wales, Cardiff; or

(b) one of the six centres which will be nationally designated and funded by the Department of Health under the auspices of the National Specialised Commissioning Advisory Group to provide a service for patients with lysosomal storage disorders;

3. Having received appropriate consent, details of patients receiving treatment will be entered into the Registry for MPS1 held by the Society for Mucopolysaccharide Diseases (the MPS Society)

Professor Roger Walker
Chairman AWMSG **1st February 2005**

This information has been disseminated by the AWMSG Secretariat.

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