UKHCDO

United Kingdom Haemophilia Centre Directors' Organisation

CAL/AT

25th March 1998

Haemophilia Directors
UKHCDO

Dear Centre Director

IMPLEMENTATION OF DOH CIRCULAR ON PROVISION OF RECOMBINANT FACTOR VIII FOR NEW PATIENTS AND CHILDREN UNDER THE AGE OF 16

I enclose a copy of the recently issued Health Service Circular (HSC1998/033) which sets out new arrangements for the provision of recombinant factor VIII (rVIII).

The Executive Committee met on Friday 20th March to consider the implementation of the recommendations. The manufacturers of rVIII have indicated that it will take up to about 6 months to provide the extra concentrate to treat all the additional patients. As there will therefore be a temporary shortage of the products the Executive Committee suggests that rVIII should be made available in the UK in the following descending order of priority.

1. Those already receiving rVIII.
2. Previously untreated patients (new patients as defined in the HSC).
3. Infrequently treated patients under the age of 16 years, e.g. mild haemophiliac requiring surgery.
4. Children less than 5 years (aim to start before the end of May).
6. Children less than 10 years (start in June/July).
7. Children less than 15 years (start July/August).

Where there is more than one child with haemophilia in a family it would be appropriate to start all family members at the same time on rVIII. This is likely to occur when the youngest begins treatment with rVIII.

Implementation will be aided if patients are given only modest stocks of concentrate to keep at home. It would be important for each Centre to keep a reasonable stock of rVIII in case there are temporary shortages in supply from the manufacturers. It is very important that once a individual starts on rVIII he does not have to switch back to plasma derived concentrate.

Chairman:
Dr Christopher A Ludlam
Department of Haematology
Royal Infirmary
Lauriston Place
Edinburgh
EH3 9YW
Tel: GRO-C
Fax:

Vice Chairman:
Dr C R M Hay
Department of Haematology
Manchester Royal Infirmary
Oxford Road
Manchester
M13 9WL
Tel: GRO-C
Fax:

Treasurer:
Dr G Dolan
Department of Haematology
University Hospital
Queen's Medical Centre
Nottingham
NG7 2UH
Tel: GRO-C
Fax:

Secretariat:
Miss Rosemary Spooner
Oxford Haemophilia Centre
The Churchill Hospital
Headington
Oxford
OX3 7LJ
Tel: GRO-C
Fax:

Registered Charity No: 1032606

As you may be aware funding for rVIII in Scotland, Wales and Northern Ireland has been more generous than in England resulting in proportionally more patients being treated in these countries. In order to continue our policy of trying to ensure treatment equity throughout the UK it is likely that fewer patients outwith England will change to rVIII in the near future.

You will see in the above guidance that we recommend starting the youngest children first on rVIII. I have indicated target dates for implementation but whether these are achieved will depend on the supply from the manufacturers. We propose to monitor the situation nationally and you will receive a circular shortly from the Paediatric Working Party seeking names of patients who have already started on rVIII and indicating how patients should be notified to a central UK register of all haemophilia children under 16 years of age.

At the Executive Committee we perceived that there may be local difficulties in purchasers obtaining the new funding for additional patients receiving rVIII; for example where Trusts (and not purchasers) are currently paying for rVIII. If difficulties are encountered these should be brought to the immediate attention of Christine Corrigan at the Health Services Directorate (address in the enclosed HSC).

If you would like to discuss any matters relating to rVIII I would be pleased to hear from you.

Yours sincerely

GRO-C

Christopher A Ludlam
Chairman