## HEALTH CIRCULAR



# DEPARTMENT OF HEALTH AND SOCIAL SECURITY

To: Regional Health Authorities Family Practitioner Committees

for action

Area Health Authorities Boards of Governors

for information

February 1976

## HEALTH SERVICES DEVELOPMENT ARRANGEMENTS FOR THE CARE OF PERSONS SUFFERING FROM HAEMOPHILIA AND RELATED CONDITIONS

#### Summary

This circular encloses a memorandum which sets out revised arrangements for the care of persons suffering from haemophilia and related conditions; lays down revised criteria for the designation of haemophilia centres; and asks Regional Health Authorities to review, in the light of these criteria, centres at which treatment is at present available to patients.

1. On 5 March 1968 a memorandum was circulated to hospital authorities, under cover of HM(68)8, listing centres which had been designated for the diagnosis, treatment and registration of persons suffering from haemophilia and related conditions and describing the functions of these centres. Following a review, which was carried out in consultation with the Directors of the present Haemophilia Centres, some alterations to the existing arrangements have been worked out and agreed and these are incorporated in the revised memorandum attached as Appendix 2.

#### Criteria for Designation as Haemophilia Centres

2. To qualify for designation, Haemophilia Centres must be able to provide clinical treatment to patients at short notice at any time of the day or night and be capable of undertaking assays of specific coagulation factors as part of their diagnostic and therapeutic procedures. With the introduction of new therapeutic agents the prospects of haemophiliacs reaching active adulthood have considerably improved and Haemophilia Centres should therefore be able to provide a wider advisory service than hitherto to haemophiliacs and their families particularly in the fields of preventive medicine and dentistry, education, employment, genetic counselling and social medicine.

### Associate Centres

3. Centres which were designated in 1968 but which do not fully meet the new criteria may nevertheless, to avoid inconvenience to patients already registered with them who live or work nearby, continue to be recognised for the purpose of giving emergency treatment. These centres will be known as Associate Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer patients a full therapeutic, diagnostic and advisory service.

#### **Reference Centres**

4. The introduction of new therapeutic agents, accompanied by the growth in experience of the treatment of haemophiliacs, has led to changes in the role of the three centres which were designated in 1968 as Special Treatment Centres. Although it is no longer necessary to refer the majority of patients to them for surgery these Centres, and a few others, have during recent years developed an advisory role towards individual Haemophilia Centres, and it has been decided that this role could usefully be officially recognised and further developed by designating them as Reference Centres and describing in some detail their functions.

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### Other facilities in the United Kingdom

5. As it is important that patients and Directors of Haemophilia Centres should be aware where treatment for haemophilia is available in the United Kingdom, haemophilia centres in Wales and Northern Ireland and regional haemophilia centres in Scotland have, with the agreement of the Welsh Office, the Department of Health and Social Services, Northern Ireland and the Scottish Home and Health Department respectively, also been included in the list of centres in England (attached as Appendix 1). The organisation of haemophilia centres in Scotland differs from that in the rest of the United Kingdom in that each centre provides the whole range of services for its area.

#### Action

6. Regional Health Authorities are asked to review, in consultation with the appropriate Reference Centre, the list of centres in England at which treatment is available to patients in the light of paragraphs 2 and 3 above and to inform the Department by 30 April 1976 which Centres are to be designated as Haemophilia Centres and which are to be known as Associate Centres.

7. Family Practitioner Committees are asked to send a copy of the attached FPN and Appendix 1 for information to all general medical and dental practitioners on their lists and to the Local Medical and Dental Committees. Enough copies are being sent separately.

8. The Department (HS2B) will continue to supply the Special Medical Card (Haemorrhagic States) and the booklet "Notes on the care of patients with hereditary haemorrhagic disorders".

From:

HS2B Division Hannibal House Elephant and Castle London SE1 6TE

01-703 6380 Ext 411

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Further copies of this document may be obtained from DHSS Store, Scholefield Mill, Brunswick Street, Nelson, Lancashire B89 0HU Tel: (0282)62411/2

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## FAMILY PRACTITIONER NOTICE

FPN 105 (HC(76)4)

# NATIONAL HEALTH SERVICE

#### GENERAL MEDICAL AND DENTAL SERVICES

#### ORGANISATION OF HAEMOPHILIA CENTRES

#### Summary

1. This Notice advises general medical and general dental practitioners of the revised arrangements for the care of persons suffering from haemophilia and related conditions; the Appendix lists the centres at which treatment is available in the United Kingdom.

#### Background

2. The arrangements under which centres are designated for the diagnosis, treatment and registration of persons suffering from haemophilia and related conditions have been in existence since 1968. Following a review which was carried out in consultation with the Directors of the present Haemophilia Centres some alterations have been agreed; the new arrangements are described in the succeeding paragraphs.

### Haemophilia Centres

3. The functions of these Centres are to provide:-

(i) a laboratory service able

(a) to carry out the tests, including the identification and assay of specific coagulation factors and anti-coagulants necessary for an exact diagnosis to be made

(b) to monitor coagulation factors and anti-coagulants during treatment

(c) in collaboration with the appropriate Reference Centre (see paragraph 7 below) to investigate relatives of patients with haemophilia or related conditions.

- (ii) a clinical service for the treatment of patients at short notice at any time of the day or night
- (iii) an advisory service to patients (and, in the case of child patients, to their parents) on matters of concern to them such as preventive medicine and dentistry, education, employment, genetic counselling and social medicine. Advice should also be given to general practitioners about the emergency treatment of haemophilic patients on their list and the procedure for securing these patients' admission to hospital when required including what the patient should do to obtain ambulance transport in an emergency.

4. A record of all patients to whom haemophilia cards are issued should be maintained at each Haemophilia Centre including at least the following information:-

- Name, address and telephone number of patient Date of birth Disgnosis Mother's maiden name
- Maternal Grandmother's maiden name
- Name, address and telephone number of general practitioner
- Name of consultant in charge of the case

### Associate Haemophilia Centres

5. Centres which were designated in 1968 but which do not fully meet the new criteria laid down for designated Haemophilia Centres (see paragraph 3 above) may wish to continue to provide emergency treatment to haemophiliacs living or working nearby and registered with them. These centres will be known as Associate Haemophilia Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer a full therapeutic, diagnostic and advisory service to haemophiliacs and their families.

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#### **Reference** Centres

6. In 1968 the centres at Oxford, Manchester and Sheffield were designated as Special Treatment Centres where special skills were available to patients requiring major surgery. At that time management during and after surgery was the most difficult aspect of the treatment of hæmophilia. This is no longer the case because the management of patients undergoing surgery has become easier as a range of therapeutic materials have become more widely available. Today the emphasis in the treatment of hæmophilic patients is on the early day-to-day care on demand and this treatment must be provided at all centres.

7. However, although it is no longer necessary to designate centres for the specific purpose of carrying out surgical treatment there are administrative and other advantages to be gained in designating some centres to be Reference Centres, to which Haemophilia Centres can look for guidance and support. The centres currently so designated and the areas which they broadly cover are:-

St Thomas' Hospital The Royal Free Hospital	)	London, the South East and East Anglia
The Churchill Hospital Oxford	)	Oxford, Wessex, the South West, the Midlands and Northern Ireland
The Royal Infirmary Manchester The Royal Infirmary with the Children's Hospital, Sheffield		The North West, North Wales, Trent and Yorkshire
The Royal Victoria Infirmary Newcastle	)	The North of England
University Hospital of Wales Cardiff	)	South Wales

- 8. The functions of these Reference Centres are:-
  - (i) to provide a 24-hour telephone advisory service to Haemophilia Centres and Associate Haemophilia Centres and to support them particularly during holiday periods
  - to provide a specialist consultant service for surgery and for orthopaedic, dental, paediatric and social care for those Haemophilia Centres and Associate Haemophilia Centres wishing to use such a service
  - (iii) to advise on and organise when called upon home therapy and prophylactic therapy for haemophilia patients
  - (iv) to provide a reference laboratory service for Haemophilia Centres and Associate Haemophilia Centres including the diagnosis of atypical cases, the assay of antibodies and the supply of assay standards and reagents
  - to provide education facilities for doctors, technicians, nurses and others as required in order to promote optimum care of patients and a comprehensive laboratory diagnostic service
  - (vi) to ensure close co-operation between the Haemophilia Centres, Associate Haemophilia Centres and the Regional Centres of the Blood Transfusion Service
  - (vii) to co-ordinate, as necessary, the allocation of available therapeutic materials to Haemophilia Centres and Associate Haemophilia Centres
  - (viii) to co-ordinate statistics collected by Haemophilia Centres and Associate Haemophilia Centres
  - (ix) to co-ordinate meetings and research programmes.

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9. Regional Health Authorities have been asked to review the list of centres in England at which treatment is at present available to patients, as shown in the attached Appendix, and to inform the Department which centres are to be designated as Haemophilia Centres and which are to be known as Associate Haemophilia Centres. As it is important that patients and others should be aware where treatment for haemophilia is available in the United Kingdom, haemophilia centres in Wales and Northern Ireland and regional haemophilia centres in Scotland have also been included in the list. The organisation of haemophilia centres in Scotland differs from that in the rest of the United Kingdom in that each centre provides the whole range of services for its area.

10. The Department (HS2B) will continue to supply the Special Medical Card (Haemorrhagic States) and the booklet "Notes on the care of patients with hereditary haemorrhagic disorders".

# January 1976

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# APPENDIX 1

# CENTRES AT WHICH TREATMENT IS AVAILABLE TO PATIENTS SUFFERING FROM HAEMOPHILIA AND RELATED CONDITIONS

### ENGLAND

Alton

Birmingham

Bournemouth

Bradford

Bristol

Cambridge

Carlisle

Coventry

Dr P G Arblaster Treloar Haemophilia Centre Lord Mayor Treloar Hospital Alton Hampshire

Department of Haematology The Children's Hospital Ladywood Middleway Birmingham B16 8ET

Dr J Stuart Department of Haematology Queen Elizabeth Hospital Edgbaston Birmingham B15 2TH

Dr D Stern Department of Pathology Royal Victoria Hospital Shelley Road Boscombe Bournemouth BH1 4JG

Dr R L Turner Haematology Department The Royal Infirmary Bradford BD9 6RJ

Dr G L Scott Department of Haematology Bristol Royal Infirmary Bristol BS2 8HW

Dr D G Chalmers Department of Haematology Addenbrooke's Hospital Hills Road Cambridge CB2 200

Dr A Inglis Department of Pathology Cumberland Infirmary Carlisle CA2 7HY

Dr N K Shinton Department of Haematology Coventry and Warwickshire Hospital Stoney Stanton Road Coventry CV1 4FH

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0420-82811

021-454-4851

021-472 1311

0202-35201 (9 am - 5 pm weekdays Ext 323. At other times please ask for doctor on call for Haemophilia Control)

0274-42200 Ext GRO-C

0272-22041 (9 am - 5 pm weekdays Ext 2614. At other times please ask for Sister-in-Charge of the Accident and Emergency Department)

0223-45151 Ext GRO-C (At night and at weekends please ask for the Duty Haematologist)

0228-23444 (Hospital switchboard will contact relevant member of team on duty)

0203-24055

512:30

Darlington

Derby

Exeter

Hull

Leeds

Liverpool

London

Memorial Hospital Darlington

Dr A E S Mustafa

Dr D A Winfield Royal Infirmary Derby

Dr J O P Edgcumbe Department of Pathology Royal Devon and Exeter Hospital Exeter EX1 1PQ

Dr C G L Raper Department of Pathology Kingston General Hospital Beverley Road Hull HU3 1UR

Dr L M Swinburne St James' Hospital Leeds LS9 7TF

Professor A J Bellingham Liverpool Royal Infirmary Pembroke Place Liverpool L3 5PU

Professor J W Stewart Bland-Sutton Institute of Pathology The Middlesex Hospital Mortimer Street London W1N 8AA

Dr R S Mibashan Haematology Department Royal Postgraduate Medical School Hammersmith Hospital Du Cane Road London W12 0HS

Professor P L Mollison Department of Haematology St Mary's Hospital Praed Street Paddington London W2 1NY

Professor J G Humble Haematology Department Westminster Hospital Dean Ryle Street London SW1P 2AP

Professor R M Hardisty Department of Haematology The Hospital for Sick Children Great Ormond Street London WC1N 3JH 0325-60100 (Hospital switchboard will contact relevant member of team on duty)

0332-47141

0392-77833 Ext GRO-C

0482-28631

0532-33144

051-709 5511

01-636 8333 (At night and at weekends please ask for the Duty Pathologist).

01-743 2030 Ext [gro.c] (At night and at weekends please ask for the Haematology Registrar on duty).

01-262 1280 Ext GRO-C

01-828 9811

01-405 9200 Ext [GRO-C] (At night and at weekends please ask for the Resident Assistant Physician).

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London (continued)

Manchester

Dr G C Jenkins Department of Haematology The London Hospital Whitechapel Road London E1 1BB

Dr Katharine M Dormandy The Haemophilia Centre The Royal Free Hospital Pond Street London NW3 2QG

Professor T A J Prankerd Haematology Department University College Hospital Gower Street London WC1E 6AU

Dr P Barkhan Department of Haematology Guy's Hospital London SE1 9RT

Professor W M Davidson Haematology Department King's College Hospital Denmark Hill London SE5 8AF

Dr C A Holman Haematology Department Lewisham Hospital High Street Lewisham London SE13 6LH

Professor G I C Ingram Department of Haematology St Thomas' Hospital London SE1 7EH

Professor P T Flute Haematology Department St George's Hospital Blackshaw Road Tooting London SW17 OQT

Dr I W Delamore Department of Clinical Haematology The Royal Infirmary Manchester M13 9WL

Dr D I K Evans Department of Haematology Royal Manchester Children's Hospital Pendlebury Nr Manchester M27 1HA 01-247 5454

01-794 0500 (After 5.30 pm and at weekends please ask for the doctor on call for the Haemophilia Centre).

01-387 9300

01-407 7600 (At night and at weekends please ask for the Resident Pathologist)

01-274 6222

01-690 4311

01-928 9292 Ext GRO-C (At night and at weekends please ask for the doctor on duty for Haemophilia)

01-672 1255

061-273 3300

061-794 4696

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Margate

Middlesbrough

Newcastle

Nottingham

Oxford

Portsmouth

Sheffield

Southampton

Sunderland

Whitehaven

Dr H Sterndale Isle of Thanet District Hospital (Margate Wing) St Peter's Road Margate Kent CT9 4AN

Dr R E Potts Middlesbrough General Hospital Ayresome Green Lane Middlesbrough Teesside TS1 5JE

Dr P Jones Royal Victoria Infirmary Newcastle upon Tyne NE1 4LP

Dr T E Blecher Dr E A French Haematology Department The General Hospital Nottingham NG1 6HA

Dr Rosemary Biggs Dr C Rizza Oxford Haemophilia Centre Churchill Hospital Oxford OX3 7LJ

Dr J R O'Brien Central Laboratory St Mary's General Hospital (East Wing) Milton Road Portsmouth PO3 6AG

Professor E K Blackburn Dr J S Lilleyman Dr F E Preston Dr H T Swan Departments of Haematology The Royal Infirmary Sheffield S6 3DA and Sheffield S6 3DA and Sheffield S10 2TH

Dr Morag Chisholm Royal South Hants Hospital Fanshawe Street Southampton SO9 4PE

Dr A MacKenzie The Royal Infirmary Durham Road Sunderland Co Durham SR2 7JE

Dr P J Whitehead West Cumberland Hospital Hensingham Whitehaven Cumberland CA28 8JG 0843-20222

0642-83133 (Hospital switchboard will contact relevant member of team on duty)

0632-25131 Ext GROCC (At night and at weekends please ask for Ward 8 (children) or Ward 13 (adults))

0602-46161 Ext and at weekends please ask for the doctor on call for Haematology)

0865-64841 Ext GROC (After 5.00 pm and at weekends please ask for the doctor on call for the Haemophilia Centre)

0705-22331

0742-20977 (At night and at weekends please ask for the doctor on call for the Haemophilia Centre)

0703-26211

0632-56256 (Hospital switchboard will contact relevant member of team on duty)

0946-3181 (Hospital switchboard will contact relevant member of team on duty) Cardiff

Belfast

Aberdeen

Dundee

Edinburgh

Glasgow

Inverness

# WALES

Dr A L Bloom Department of Haematology University Hospital of Wales Heath Park Cardiff CF4 1XW

## NORTHERN IRELAND

Professor M G Nelson Department of Haematology Royal Victoria Hospital Grosvenor Road Belfast BT12 6BA

### SCOTLAND

**Regional Haemophilia Centres** 

Dr Audrey A Dawson Haematology Unit University Medical Buildings Foresterhill Aberdeen AB9 2ZB

Dr G R Tudhope Wards 5/6 Ninewells Hospital Dundee DD1 9SY

Professor R H Girdwood University Department of Therapeutics The Royal Infirmary Edinburgh EH3 9YW

Dr S H Davies Department of Haematology The Royal Infirmary Edinburgh EH3 9YW

Dr C R M Prentice Department of Medicine Royal Infirmary Glasgow G4 0SF

Dr I A Cook Regional Blood Transfusion Centre Raigmore Hospital Inverness IV2 3UJ 0222-755944 (After 5 pm and at weekends please ask for the House Physician to the Haematology Department)

0232-40503

0224-23423 Ext GRO-C

0382-60111 Ext GRO-C

031-229 2477 Ext GRO-C

031-229 2477 Ext GRO-C

041-552 3535 (If not available ask for the Receiving Physician)

0463-34151

# MEMORANDUM ON THE FUNCTIONS OF HAEMOPHILIA CENTRES

1. In the memorandum attached to HM(68)8 a description was given of the functions of a number of centres, known as Haemophilia Diagnostic and Registration Centres, which were designated for the diagnosis, treatment and registration of persons suffering from haemophilia and related conditions. It has been decided to make some changes in the existing arrangements and these are described in this memorandum.

#### HAEMOPHILIA CENTRES

2. The functions of these Centres are to provide:

(i) a laboratory service able

(a) to carry out the tests, including the identification and assay of specific coegulation factors and anti-coegulants necessary for an exact diagnosis to be made

(b) to monitor coagulation factors and anti-coagulants during treatment

(c) in collaboration with the appropriate Reference Centre (see paragraph 6 below) to investigate relatives of patients with haemophilia or related conditions

- (ii) a clinical service for the treatment of patients at short notice at any time of the day or night
- (iii) an advisory service to patients (and, in the case of child patients, to their parents) on matters of concern to them such as preventive medicine and dentistry, education, employment, genetic counselling and social medicine. Advice should also be given to general practitioners about the emergency treatment of haemophilic patients on their list and the procedure for securing these patients' admission to hospital when required including what the patient should do to obtain ambulance transport in an emergency.

3. A record of all patients to whom haemophilia cards are issued should be maintained at each Haemophilia Centre including at least the following information:

> Name, address and telephone number of patient Date of birth Diagnosis Mother's maiden name Maternal Grandmother's maiden name Name, address and telephone number of general practitioner Name of consultant in charge of the case

## ASSOCIATE CENTRES

4. Centres which were designated in 1968 but which do not fully meet the new criteria laid down for designated Haemophilia Centres (see paragraph 2 above) may wish to continue to provide emergency treatment to haemophiliacs living or working nearby and registered with them. These centres will be known as Associate Centres. Each will be linked with a convenient designated Haemophilia Centre so that together they will be in a position to offer a full therapeutic, diagnostic and advisory service to haemophiliacs and their families.

# **REFERENCE CENTRES**

5. In 1968 the centres at Oxford, Manchester and Sheffield were designated as Special Treatment Centres where special skills were available to patients requiring major surgery. At that time management during and after surgery was the most difficult aspect of the treatment of haemophilia. This is no longer the case because the management of patients undergoing surgery has become easier as a range of therapeutic materials have become more widely available. Today the emphasis in the treatment of haemophilic patients is on the early day-to-day care on demand and this treatment must be provided at all centres.

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6. However although it is no longer necessary to designate centres for the specific purpose of carrying out surgical treatment there are administrative and other advantages to be gained in designating some centres to be Reference Centres to which Haemophilia Centres can look for guidance and support. The centres currently so designated and the areas which they broadly cover are:

St Thomas' Hospital The Royal Free Hospital	)	London, the South East and East Anglia
The Churchill Hospital Oxford	)	Oxford, Wessex, the South West, the Midlands and Northern Ireland
The Royal Infirmary Manchester The Royal Infirmary with the Children's Hospital Sheffield	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~	The North West, North Wales, Trent and Yorkshire
The Royal Victoria Infirmary Newcastle	}	The North of England
University Hospital of Wales Cardiff	)	South Wales

- 7. The functions of these Reference Centres are:
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  - to provide a specialist consultant service for surgery and for orthopaedic, dental, paediatric and social care for those Haemophilia Centres and Associate Centres wishing to use such a service
  - (iii) to advise on and organise when called upon home therapy and prophylactic therapy for haemophilia patients
  - (iv) to provide a reference laboratory service for Haemophilia Centres and Associate Centres including the diagnosis of atypical cases, the assay of antibodies and the supply of assay standards and reagents
  - (v) to provide education facilities for doctors, technicians, nurses and others as required in order to promote optimum care of patients and a comprehensive laboratory diagnostic service
  - (vi) to ensure close co-operation between the Haemophilia Centres, Associate Centres and the Regional Centres of the Blood Transfusion Service
  - (vii) to co-ordinate, as necessary, the allocation of available therapeutic materials to Haemophilia Centres and Associate Centres
  - (viii) to co-ordinate statistics collected by Haemophilia Centres and Associate Centres
  - (ix) to co-ordinate meetings and research programmes

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