RH.B. file ref: 248

NEWCASTLE REGIONAL HAEMOPHILIA SERVICE

NEWCASTLE AREA HEALTH AUTHORITY

THE ROYAL VICTORIA INFIRMARY

QUEEN VICTORIA ROAD NEWCASTLE UPON TYNE NEI 4LP

(2)

TELEPHONE NEWCASTLE 25131 Ext. 773 STD 0632

HAEMOPHILIA CENTRE

Mark

Dear Dr Sackwood

DHSS listing of Centres

DEPARTMENT OF HAEMATOLOGY

MIDITAL COMMETURAL

For information

I enclose a copy of the information sent at their request to the DHSS for inclusion in a revised list of Haemophilia Centres in the UK, and hope that the details meet with your approval. You will see that only hospital telephone numbers are given as restrictions in space prevent a full list of all team specialists. I would be grateful if arrangements could therefore be made in the Sub-regional Centres for the switchboards to be notified of individual on call arrangements for haemophilia.

Regional Survey

With minor amendments the scheme for the service seems to have met with the approval of hospital staff. The enquiry into the number of patients with hereditary bleeding disorders in the Region is progressing well and I enclose a list of people known up to April 1974. Please would you keep us informed of any amendments or new patients. A fair number of people still require laboratory investigation (particularly factor assays) and we will gradually work through the list. We also intend to issue new DHSS haemorrhagic disorders cards to everyone with details of the new arrangements.

Hardbook

The Haemophilia Centre is now in operation in the RVI and you will be most welcome at any time. We are preparing a small handbook on clinical and laboratory aspects of haemophilia which we hope will be of use to junior staff, and will also help to standardise procedures throughout the Region. This should be ready soon and it might be appropriate to arrange an informal meeting of everyone concerned to discuss this and other aspects of the service later in the year.

Factor concentrates

Two firms, Serological Laboratories (Immuno - "Kryobulin") and Travenol Laboratories ("Hemofil") received licences to market VIII concentrates in November 1973. Both products are HAA tested. Because of their small volume and 4°C storage they are ideal for home therapy, and are also useful as a back-up supply to Cryoprecipitate and fresh frozen plasma. Twenty-three patients (names appended) are now on home therapy using Hemofil.

These commercial concentrates are very expensive (£°5 per 250 units) and because of this we suggest that all stocks for the Region should be ordered through, and distributed by, the RVI. Sister Maureen Fearns has the day to day responsibility for the home therapy programme and maintenance of the concentrate stock and queries should be directed to her. To date we have sent batches of 10 vials Hemofil to Middlesbrough and Whitehaven with arrangements to change to fresh \$tock in time for the RVI to use any surplus

Several firms are trying to market concentrates of factors II, (VII) IX. X for the treatment of Christmas disease and the correction of prothrombin complex deficiency - particularly in liver disease. Once again these commercial concentrates are very expensive, and we obtain a free supply of the excellent Oxford product from Dr Bidwell. This is on 'clinical trial' to prevent wastage and is only available to Centres able to perform factor IX assays.

Yours sincerely

Kind regards

before the expiry date.

Peter Jones

- Encl. 1) Information sent to DHSS for publication
 - 2) Register of patients
 - 3) List of teams
 - 4) Home therapy instructions as issued to patients
 - 5) Names of patients on home therapy (July 1974)

Newcastle Regional Haemophilia Service (covers Cumbria, Cleveland,

Durham, Northumbria, and Tyne and Wear)

Regional Reference Centre: Dr Peter Jones

Royal Victoria Infirmary Newcastle upon Tyne NE1 4LP

Newcastle 0632 25131 Ext GRO-C

(During normal working hours the Centre Sister may be contacted by 'bleep'; at night and weekends please ask for ward 8(children) or ward 13(adults)).

Sub-regional Centres

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

Carlisle: Cumberland Infirmary 0228 23444

Darlington: Memorial Hospital

0325 60100

Middlesbrough: General Hospital

0642 83133

Sunderland: Royal Infirmary

0632 56256

Whitehaven: West Cumberland Infirmary

0946 3181

LIST OF TEAMS

Carlisle: Cumberland Infirmary

Physician

Dr T C Studdert

Paediatrician

Dr F M Elderkin

Pathologist

Dr A Inglis

Dental Surgeon

Mr S C Banerjee

Darlington: Memorial Hospital

Physician

Dr J Hampson

Paediatrician

Dr H J Heggarty

Pathologist

Dr J Tragillus A.E.S Mutula

Dental Surgeon

Mr G B Summersgill

Middlesbrough: General Hospital

Physician

Dr A A Williams

Paediatrician

Dr M M Oo

Pathologist

Dr R E Potts

Dental Surgeon

Mr G B Summersgill

Newcastle: Royal Victoria Infirmary

Director

Dr P Jones

Secretary

Miss M Latham

Sister

M A Fearns

Social Worker

Mr W Morgan

General Surgery

Mr L B Fleming

Orthopaedic Surgery

Mr G D Stainsby

Physiotherapist

Miss S Coles

Mr I Geffner (adults)

Dental Surgeons

Mr J R Porteous (children)

Research Secretary

Mrs S M Lewis

Sunderland: Royal Infirmary

Physician

Dr R H Vasey

Paediatrician

Dr J B Heycock (Children's Hospital)

Pathologist

Dr A MacKenzie

Dental Surgeon

Dr R Kerr-Gilbert

Whitehaven: West Cumberland Hospital

Physician

Dr J Simpson; Dr C B I Willey

Paediatrician

Dr J W Platt

Pathologist

Dr P J Whitehead

Dental Surgeon

Mr S C Banerjee

Newcastle Regional Haemophilia Service

HOME THERAPY

You are about to start treating yourself at home with antihaemophilic factor concentrate. The material provided has been processed from human blood and costs the National Health Service about 10p per unit. If it is used sensibly this high cost should be offset by savings in ambulance and hospital time. Your training and the following notes will help you to use home therapy safely and effectively. If ever you experience difficulty do not hesitate to contact one of the Centre staff.

The kit

The following items will be supplied with the concentrate and diluent:

- 1. Record keeping book.
- 2. Dry cotton wool balls.
- 3. Medi-swabs (soaked in antiseptic)
- 4. Plastic syringes- 20 mls. - 2 mls
- 5. Filter needles (in concentrate pack)
- 6. Double-ended needles(in concentrate pack)
- 7. Small vein sets.
- 8. Disposable needles.
- 9. Needle disposal box.
- 10. Tourniquet.
- 11. Paper adhesive tape (Micropore) and band-aids.
- 13. Piriton for IV injection.
- 13. Thermometer.

Indications for home therapy

Home therapy should be given in the event of:

- 1. Bleeds into joints.
- 2. Bleeds into muscles.
- * 3. Injury to mouth, tongue, face, eyes or neck.
- * 4. Severe knocks to the head or unusually severe headache.
- * 5. Prolonged bleeding from any site.
- * 6. Severe swelling in any site.
 - 7. Open wounds with prolonged bleeding.

If you think you are bleeding do not hesitate to administer concentrate; the earlier bleeds are treated the better.

Home therapy by itself is suitable for uncomplicated joint and muscle bleeds and for bleeding from cuts which do not require stitches. In the event of any other bleed (* see above) you should contact the Centre as soon as

possible. -2

Method for giving concentrate

Check that all the items you will need are within reach. Ask a responsible person to be present while you give yourself the concentrate. Make sure you are in a comfortable position before starting.

- 1. Warm both bottles in warm water (37°C) for approximately 5 minutes.
- 2. Remove from water and take off the metal caps.
- 3. Wipe tops of bottles with antiseptic swab (Medi-swab).
- 4. Remove plastic cover from one end of <u>double ended needle</u>; take care not to touch exposed needle. Insert needle through diluent bottle so that the needle lumen is just inside the cap.
- 5. Remove other plastic cover from double-ended needle. Invert diluent bottle over concentrate bottle and push exposed needle into concentrate bottle. The vacuum in the concentrate bottle will draw in diluent.
- Disconnect the two bottles by removing needle from the concentrate bottle stopper.
- 7. Gently rock and rotate concentrate bottle until concentrate is dissolved. (Vigorous shaking will lower factor VIII activity). If, after 10 minutes, there are still lumps in the bottle move it in warm water (37°C) for a few minutes to help dissolve them.
- 8. Attach <u>filter-needle</u> to 20 ml syringe; wipe concentrate bottle top with antiseptic; insert needle, invert bottle, and withdraw fluid. (It may be necessary to inject some air into the bottle to aid withdrawal.) Take care not to touch needle.
- 9. Remove filter-needle and attach small vein set to the syringe.
- 10. Remove small vein set needle guard and place to one side. Take care not to touch the needle.
- 11. Holding syringe vertically (plunger down) gently push plunger in until fluid just reaches the tip of the needle. This expels the air from the syringe and tubing; the injection of air would be dangerous. Replace needle guard until ready to give injection.
- 1º. Sit or lie in a comfortable position. Tear off a strip of paper adhesive tape ready for holding the needle in place, and put a band aid and a dry cocton wool ball near at hand.
- 13. Apply tourniquet about 10 cms above chosen vein. Vein should be visible, filled and prominent.
- 14. Swab the skin over and around vein with antiseptic.
- 15. Remove needle guard and gently insert needle into vein. The syringe may rest on a table or in your lap while venepuncture is performed. When using an elbow vein keep arm straight at the elbow;

- 16. Release the tourniquet.
- 17. Slowly inject fluid. If this is painful, or a swelling appears at the injection site, the fluid is entering the tissues and not the blood stream; another venepuncture will be necessary if the needle cannot be readjusted in the vein.
- 18. If palpitations or other unusual feelings are experienced during the injection stop and wait for a minute or two before proceeding. The minimal injection rate should be 3 minutes for each 10 mls of fluid.
- 19. When infusion is completed place a dry cotton wool ball over injection site; withd aw needle and apply pressure to site for 2 minutes keeping arm elevated. Apply band aid and press for further 2 or 3 minutes.

After treatment

When infusion is complete, and you are satisfied that the injection site is sealed and not likely to bruise, the following procedure should be carried out:

- Place all needles (including small vein set) in needle disposable box.
- Place syringe, bottles and dirty dressings in plastic pack. (If you have a suitable fire the syringes and dressings may be burnt.) Seal the pack.
- Return the needle disposal box and plastic packs to the Centre, or to your nearest hospital. Do not put them in the dustbin or refuse sack.

NOTE There is a very real danger of infection from used syringes and needles, and cases in which serum hepatitis has been caught by other members of the family are known. All equipment must be kept out of the reach of children and syringes must NEVER be washed out and given to children for use as water pistols. Even the most careful washing will not remove the virus responsible for the disease.

Allergic reactions

These are rare with concentrate but if they occur an injection of Piriton should be given into a vein as directed by the Centre doctor. The injection is given using a 2 ml disposable syringe and needle. Disposal of the ampoule syringe and needle is as above.

Record keeping

Please keep a record of all treatment. Further supplies will only be issued on return of the record book to the Centre. If for any reason a dose is made up and not used this should be recorded.

The following information is required:

- 1. Batch number of concentrate (on bottle)
- Expiry date of concentrate (on bottle)
- 3. Date and time of treatment
- 4. Dose given (in units shown on bottle)
- 5. Reason for treatment: site of bleed

cause of bleed

time bleed started

- 6. Difficulties in treatment (mixing or injection)
- Side effects e.g. temperature, palpitations, sweating, headache etc
- Measures taken to dea with side effects e.g. slowing infusion Piriton injection etc.
- 9. Effectiveness of treatment.

Storage

The factor concentrate has to be kept in a fridge (NOT in a deep freeze). If you are travelling it may be taken in a cool container and put back in a fridge as soon as possible. Provided the seals on the bottles are not broken and the bottles intact the packs of concentrate may be stored in an ordinary domestic fridge without danger to others. Used bottles or other equipment must never be allowed to come into contact with food because of the danger of serum hepatitis transmission.

Sister Maureen Fearns

Dr. Peter Jones

November 1973

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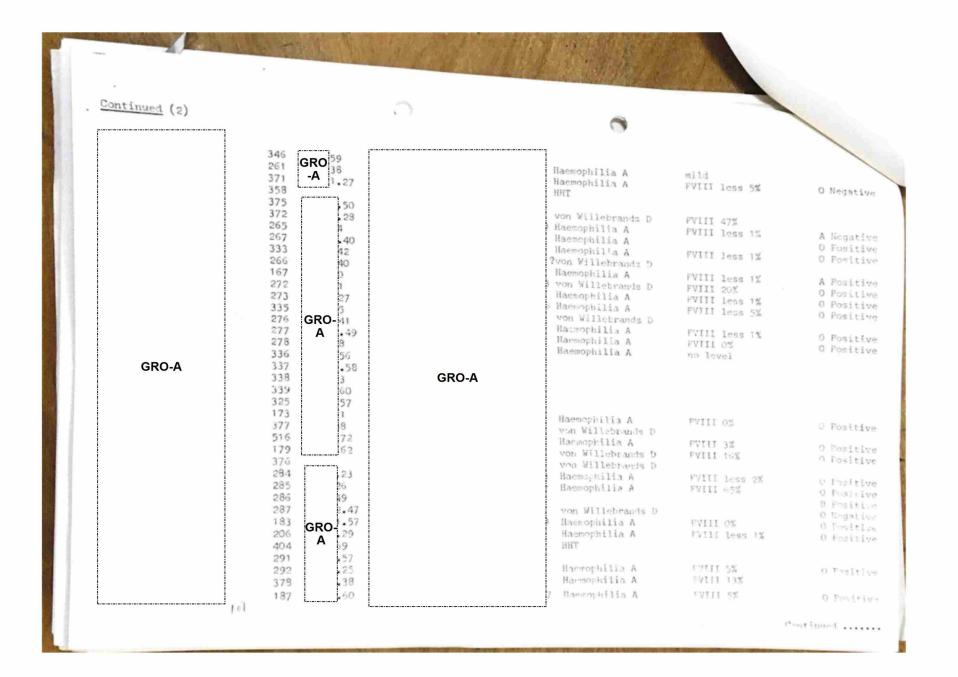
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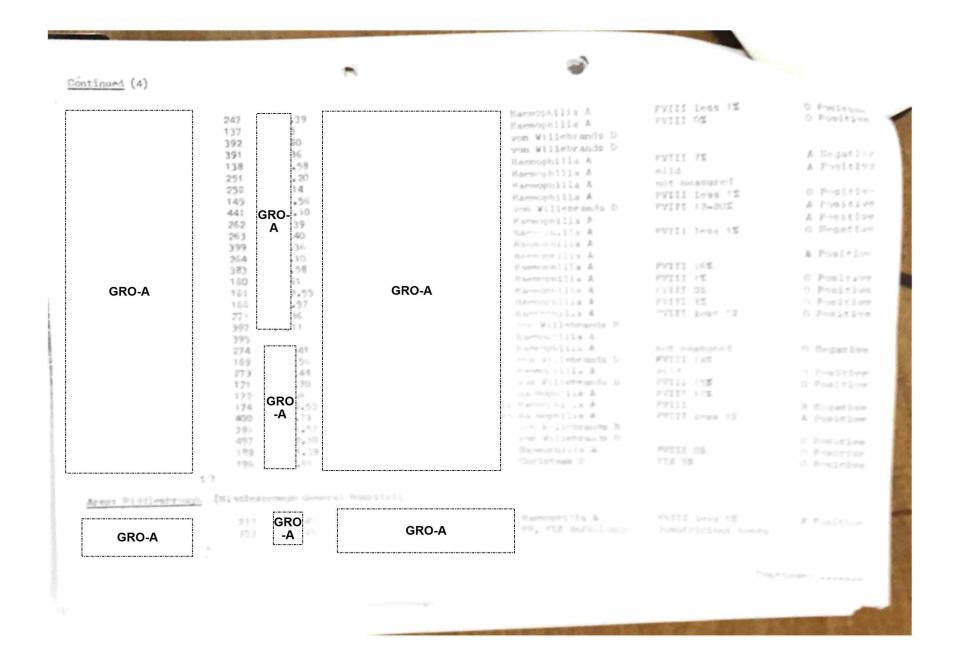
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