ACCESSION No.: LHB37/2e/43
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Lothian Health Board

J. Barrie

Your ref :
Our ref :
If calling ask for: Mr. Barrie
Date : 2nd December, 1982

11 Drumsheugh Gardens
Edinburgh EH3 7QQ
Telephone:
031-225 1341

IN CONFIDENCE

Dear Sir/Madam,

A Meeting of the Area Executive Group will be held at 9 a.m. on Tuesday 7th December, 1982 in Committee Room 1, 11 Drumsheugh Gardens, Edinburgh.

Yours faithfully,

J. BARRIE

Assistant Secretary

A G E N D A

Apologies for Absence.

1. Minutes of Meeting held on 16th November, 1982 - (previously circulated).
2. Capital Works - (report enclosed).
3. Strategic Planning Group - (report enclosed).
4. Health Services Act 1980:
   (i) Section 50 Agreement - (copy letter dated 26.11.82 from SHHD enclosed).
   (ii) Private Practice in Health Board Area - (copy letter dated 29.11.82 from SHHD enclosed).
5. Royal Victoria Hospital - Phase III - (report enclosed).
6. New Developments in Health Care - Computer Assisted Diagnosis and Audit Project - (report enclosed).
7. Amendment of Mental Health (Scotland) Act 1960 - (report enclosed).
8. Case for the Appointment of a Staff Nurse - Edinburgh Haemophilia Centre - (report enclosed).
9. Care of Children of Health Board Nursing Staff - (report enclosed).
10. Combined Pay Department - Staffing
11. Energy Conservation - (report enclosed).
12. Staff Vacancies - (restricted enclosure).

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13. College Based Sandwich Course Students - Proposed Increase in Lothian Health Board Payments - (restricted enclosure).

14. The Occupational Health Service - (paper to follow).

15. Consultant in Terminal Care - St. Columba's Hospice - (restricted enclosure).

16. Young Chronic Sick Unit, Liberton Hospital - (restricted enclosure).

17. Bangour Hospitals - Assisted Travel Scheme - (previously circulated 29.11.82).

18. Study of Pathways into and between Services for the Elderly (previously circulated 25.11.82).

19. Speakers Following Board Meetings - (previously circulated 24.11.82).

20. Matters Arising and Carried Forward List - (enclosed).

21. Any Other Competent Business. Emergency Dental Service.

22 Designated Medical Officers:

23 [illegible] Oct 82;

~~24 [illegible]~~ ? next meeting

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LOTHIAN HEALTH BOARD

Area Executive Group
7th December, 1982

Case for the Appointment of a Staff Nurse:
Edinburgh Haemophilia Centre

Haemophilia is a chronic disease which can be effectively treated by infusions of Factor VIII. Patients are either treated in hospital, for acute bleeds or surgery, or at home for minor bleeding episodes. By providing a good treatment service the aim is to maintain patients at work, school, and at home, so that they lead a full life, contributing normally to both family and every day life.

In the United Kingdom, treatment is organised through NHS/SHHD designated Haemophilia Centres. The Edinburgh Haemophilia Centre is one such centre, and it is now generally accepted that all large centres, such as the recognised supra-area Haemophilia Reference Centre located in the Edinburgh Royal Infirmary, should, in addition to a Director, have active nursing involvement, social service input and physiotherapy. Other major Haemophilia Centres have at least one nurse, and in some two or three nurses are employed. While the Director of the Edinburgh Haemophilia Centre (Dr. C.A. Ludlam) has sessions provided by a social worker (Miss E. Vose) and physiotherapists (Mr. A. Rae and Mr. J. Robson), there is no nurse with a dedicated appointment to the centre.

A development case was promoted in South Lothian District for the appointment of a staff nurse, based at the Edinburgh Haemophilia Centre, and particularly concerned with the care of the haemophiliac patients in the community. The case was included in the South Lothian District development submissions for 1982/83, as a District priority I, at a total cost of £9,500 annually, including £3,000 for travel expenses. Because of the extremely restricted development money available in this current financial year, the Board were unable to fund this development. The development, however, remains a priority. Revised costings to include the 7½% pay offer, and an element for inflation, bring the total cost to £10,250.

A draft job description has been prepared and is at Annex A. It will be noted that the staff nurse would be responsible to the Director and appropriate administrative links have been identified.

The case is now promoted as a development which should be self-financing, in that the employment of a staff nurse would be expected to result in a significant reduction in the use of factor VIII, and particularly result in a reduction in the use of commercial factor VIII, which is presently required to supplement the allocation of intermediate factor III (provided at no cost to the Board from the Protein Fractionation Centre (PFC) at Liberton).

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The present requirement for factor VIII concentrate is approximately 130,000 i.u. per month, while the allocation of factor VIII from PFC to the Edinburgh Haemophilia Centre is only 84,000 i.u. The difference has to be made up by the purchase of commercial factor VIII, at a cost of £2,500 per month.

It is considered that home supervision of haemophiliacs will significantly reduce the total demand for factor VIII since it is frequently inadequate supervision that results in the need for hospitalisation and the consequential use of factor VIII in high dosage. It is anticipated that the better supervision of haemophiliacs which could be achieved by the employment of a staff nurse would result in at least a 15% reduction in factor VIII consumption, amounting to a reduction of about 20,000 i.u. per month, which is equivalent to a saving of about £12,000 per year. The improved home surveillance would also result in savings in the ambulance costs of frequent hospital visits, and would permit certain patients to be treated at home instead of, as at present, in acute hospital beds. These savings would be significant, although they might not be seen directly in the Board's accounting statistics. The improved home surveillance would also result in a considerable improvement of the quality of life for haemophiliacs.

Case examples suggest that improved surveillance could result in a reduction of the use of factor VIII, and in better patient care. (Annex B).

It is understood that commercial blood products to treat haemophiliacs to the value of about £40,000 was purchased in the first half of this financial year.

It is recommended that a staff nurse be appointed to the Edinburgh Haemophilia Centre at a cost of £10,250 including travel expenses, to be funded from the anticipated savings in the use of commercial factor VIII.

IMO/340/6
29th November, 1982

Dr. I.M. Ogilvie
Community Medicine Specialist

ANNEX A

Draft Job Description - Staff Nurses: Edinburgh Haemophilia Centre

The staff nurse would be based in the Haemophilia Centre in Ward 23, Royal Infirmary of Edinburgh, but a principal responsibility would be for the supervision of haemophiliacs within the community.

The staff nurse would be responsible to the Director of the Edinburgh Haemophilia Centre for the clinical aspects of the work, but administrative links would be through the Department of Nursing at the Royal Infirmary of Edinburgh.

In the community the staff nurse would be responsible for the supervision of home therapy patients and would visit these patients regularly at home. The establishment of a good liaison between the community medical and nursing services is important and would be a responsibility of the nurse, working closely with the other branches of the Health Service in the community. These duties would be to ensure that conditions for patients to treat themselves are adequate at home, at work/school, and to ensure that relatives, employers and teachers are well informed and reassured about haemophilia. In particular the staff nurse would ensure that haemophiliacs were carrying out adequately self-surveillance and self-treatment when applicable.

In relation to home therapy the staff nurse would teach patients (or parents) how to prepare factor VIII concentrates and inject themselves intravenously and safely. The nurse would educate patients (and parents) which type of bleeds require treatment and how much therapy should be given, and organise the supply of factor VIII for home treatment and the assessment of the use of therapeutic materials.

The staff nurse would be responsible in hospital for duties related to acute bleeding and the need for surgery. The staff nurse would supervise the treatment of acute bleeds in out-patients and in-patients in conjunction with the on-call doctor, collect necessary blood samples to assess the response to treatment, and co-ordinate and supervise treatment of patients undergoing surgery.

The staff nurse would be responsible for assisting at out-patient review clinics, and in carrier detection. The staff nurse would assist with the collection of family history data and blood samples in order to identify carriers of haemophilia.

The staff nurse would assist secretarial staff with the collection and recording of treatment records, and assess the response of treatment of individual joint bleeds from the records.

ANNEX B

Illustrative Case Examples

The following brief descriptions are given as examples of typical cases in which it is believed that the closer supervision and surveillance which could be provided by a staff nurse carrying out home surveillance could have resulted in considerable savings of the need for factor VIII, as well as considerable benefit to the patients in terms of a better quality of life.

CASE NO. 1

A 35 year old university graduate working in a sedentary occupation was on home therapy for severe haemophilia A. Most haemarthroses in knees and elbows settled with one, or at most two, injections of factor VIII which he administered to himself. In the Autumn of 1980 he had recurrent haemarthroses into his right knee each of which only partially settled with therapy. Repeated supplies of factor VIII were obtained as usual from hospital but on each occasion when he came to collect it he was not seen by any medical or nursing staff. It was therefore not appreciated by the hospital staff that he had a chronic haemarthrosis of 3 months duration until he attended a routine follow-up review clinic in the out-patient department. It took 9 months for this chronic haemarthroses to settle with frequent hospital visits and 120,000 i.u. factor VIII was used at a cost of over £6,000. This is four times the annual factor VIII consumption for an average severe haemophiliac. One of the responsibilities of a Haemophilia Nurse would be to see each haemophiliac when further supplies for home therapy are collected and thereby ascertain whether all recent bleeds have responded to therapy.

CASE NO. 2

A 15 year old school boy with severe haemophilia living 10 miles from Edinburgh had recurrent painless haemarthroses into his left knee. Because the bleeds caused relatively little discomfort the father was reluctant to bring him to the Haemophilia Centre for factor VIII therapy. Although his general practitioner was very attentive he was of little help because he was unfamiliar with haemophilia and its treatment. Furthermore the boy was missing considerable schooling because of his haemophilia at a critical time in his education. Failure to gain school leaving certificates may well render him unemployed as he is not medically fit for manual work because of his haemophilia. For his knee conventional medical therapy was initiated including attempts to administer factor VIII regularly but because of ignorance, misunderstanding and unreliability of his parents treatment was ineffective and reluctantly it was decided that he should be a synovectomy.

The factor VIII therapy alone for this operation costs at least £2,500 and to this must be added the cost of surgery and in-patient stay in hospital of over a month.

A haemophilia nurse could have visited the patient and his family at home firstly to explain the importance of therapy and secondly to arrange either for the boy to receive treatment at home or by his general practitioner. Regular and frequent review by the nurse both at the Haemophilia Centre and at home would allow therapy to be assessed and appropriate action taken if compliance with treatment was suboptimal.