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NEWS BULLETIN

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TREATMENT OF HAEMOPHILIA

During the past few weeks there has been a good deal of correspondence in the "Lancet" which has highlighted how the financial troubles of the National Health Service are affecting the supplies of materials used for the treatment of haemophilia.

A detailed and comprehensive letter from Dr. Rosemary Biggs of Oxford stated that because of the shortage of material 90% of haemophilic patients in the United Kingdom are receiving less than the optimum treatment for their complaint. Essential but non--urgent operations are being postponed and delay is arising in putting patients on to home treatment. Other doctors have written giving their views, as has the Haemophilia Society. Some of these letters are reproduced on pages 3, 4 and 5 of this Bulletin.

To draw the attention of the Secretary of State of the Department of Health and Social Security, The Rt. Hon. Mrs. Barbara Castle, M.P., to the situation, questions were asked in the House of Commons on 9th July 1974 by Mr. Lewis Carter-Jones (Labour-Eccles) which produced the following statement from Dr. David Owen, the Parliamentary Under-Secretary of State:-

> "The supply of Factor VIII produced within the National Health Service is at present insufficient for the optimum treatment of haemophilic patients. I hope that it will be possible to increase our supplies and meanwhile product licences were issued last year to two firms to market imported FactorVIII in the United Kingdom. Adequate stocks, I understand, are held of this commercial material. It is not the Department's normal practice to make central purchases of health service supplies but central contracts were arranged to facilitate the purchase of this material by health authorities. I recognise the desirability of enabling these patients to receive treatment at home but progress in this direction is likely to depend largely on the extent to which production of Factor VIII within the National Health Service can be increased".

A further question from Hon. C. M. Woodhouse (Conservative-Oxford) produced a similar reply.

Surely it is ludicrous that a Minister should state that there are "adequate stocks" of commercially produced Factor VIII, imported under licences issued by the Government, in the knowledge that it cannot be purchased by most hospitals because the necessary money is not available.

The figure of £1-2 million which it is estimated would purchase sufficient commercially produced material to adequately supplement that made by the N.H.S. is a tiny drop in the ocean of the total expenditure which in the year 1972-3 reached almost £3,000 million. It is, for example, a small fraction of the amount it is estimated will be lost to the N.H.S. by the phasing out of private patient beds. Whether or not you agree with this it is a matter for speculation why, if money can be forfeited for what it is claimed is a point of moral principle, it cannot, apparently, be just as easily found for what, in this instance, might be the principle of saving a life or preventing the crippling of a young child.

The general discontent which is rife throughout the N.H.S. at the present time does not help in finding a solution to our problem. When the Haemophilia Society recently offered a hospital assistance in the form of voluntary workers to help in increasing the production of cryoprecipitate, we were told that such help might well be resented by the laboratory technical staff to such an extent that "industrial action" could be the result. Some may be shocked by this attitude but who can say they would not have similar feelings if, like so many in the hospital service, they were in a job in which they are overworked, underpaid, and feel they are being taken advantage of because they have more conscience about their responsibilities than other more powerful sections of the community.

If there is to be an answer to the problem affecting haemophiliacs then we must see to it that those in public office are aware of the facts. We therefore urge all members to write to their Member of Parliament, or if by the time you receive this Bulletin we are in the throes of a General Election, write to all your prospective candidates. Such pressure will ensure that all in the House of Commons will at least be aware of the present deplorable situation.

We can only hope that this knowledge will prompt some to take action which will contribute towards achieving a solution.

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The letters on Pages 3, 4 and 5 and the article on carriers on Page 5 are reproduced with grateful acknowledgments to the Editor of the "LANCET".

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We will be pleased to send a further copy of this News Bulletin to any member upon request.

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3rd EUROPEAN REGIONAL CONGRESS - WORLD FEDERATION OF HEMOPHILIA

An ambition of many people was realised when our Society was privileged to host the first Congress held in the country in the name of the World Federation of Hemophilia.

During the 27th/28th/29th April 1976 over 300 doctors, scientists, social workers, nurses, technicians, heamophiliacs and their families, from 17 different countries, gathered together in London, to listen to the distinguished speakers and to participate in general discussion.

We were most fortunate that Professor R.G. Macfarlane, former Director of the Medical Research Council's Blood Coagulation Research Unit at Oxford, renowned throughout the world as the man who for many years led the way in haemophilia research and treatment, was present to perform the opening ceremony. This was followed by Professor G.I.C. Ingram who spoke on "The History of Haemophilia", covering the period from the earliest descriptions in ancient writings to the present time, and the development of modern treatment. The paper was to be published by the British Journal of Clinical Pathology and an advance copy was presented to each delegate.

The entire afternoon session of the first day was chaired by Dr. Peter Jones and covered "The organisation and role of the Haemophilia Centre in the comprehensive care of the Haemophiliac". Members of the staff of the Newcastle Haemophilia Centre including a laboratory technician, social workers, a nursing sister, a physiotherapist, a psychiatrist, a dentist, and a surgeon presented papers on the various aspects of their work. Dr. Peter Jones was presented with a special award by Mr. Henri Chaigneau, President of the French Haemophilia Association, for his work on haemophilia.

On the second day the morning session was on "The preparation and optimum use of blood products" and in the afternoon we heard of "Behavioural problems and those of relationships, education, rehabilitation and genetics". During the latter session we were honoured by the presence of our Patron, H.R.H. The Duchess of Kent, accompanied by her Lady in Waiting, Miss Jane Pugh. Her Royal Highness was introduced to many of the delegates and was obviously most interested in talking to the mothers of haemophiliacs.

On the third day we had sessions on "Social Work" and "The future - a realistic look at the possibilities for the care of haemophiliacs in the next few years". At the close of this session, Dr. David Owen, M.P., Minister of State at the Department of Health, congratulated the Society on organising the Congress and gave an assurance that it was the policy of his Department to see that the United Kingdom would eventually be self-supporting in the production of blood products for the treatment of haemophilia.

Since the close of the Congress we have received many letters congratulating us on its organisation, commenting upon the many interesting and varied papers, and the happy and encouraging atmosphere. Our intention to devote the majority of the time available to social problems and subjects more readily understood by lay delegates, was obviously successful.

We are most grateful to all those doctors who gave their support and among the many others to whom thanks are due we particularly mention the ladies who staffed the reception desks, the nurses who staffed the emergency treatment room, the volunteers who provided an emergency 24-hour car service, the members who acted as interpreters and stewards and of course, the Organising Committee who gave so much of their spare time to arrange what proved to be such a worthwhile and memorable event.

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The proceedings of the Congress are being published at a price of £10.50 and an order form is enclosed.

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We have purchased a quantity of the interesting and informative paper presented by Professor G.I.C. Ingram, "The History of Haemophilia". These have been specially produced for us and anyone requiring a copy (free of charge) need only send their request accompanied by a 6½p stamp.

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A specially printed News Bulletin, giving more precise information about the Congress, will be sent to all members in the New Year.

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