THE HAEMOPHILIA SOCIETY

P.O. BOX 9 · 16 TRINITY STREET · LONDON, SE1 1DE
Telephone: 01-407 1010

NEWS BULLETIN

JANUARY 1972

On the 1st January, 1972, among the New Year Honours in the Prime Minister's list, there was announced the award of the M.B.E. to K.R. Polton, Honorary Treasurer of The Haemophilia Society.

The news is great and welcome news to members of the Society and to all friends of haemophiliacs for two good reasons. One is that personal recognition has been given to a man who for so long has served the interests of haemophiliacs with persistence, watchfulness, imagination and good sense. The years of his work for our cause are now approaching a quarter of a century. The hours he has spent in it never will and never can be counted. He is indeed the principal architect and builder of the Society as it stands today; and all this has been done in what should be his leisure time, for he is also, like many other good haemophiliacs, holding down a not inconsiderable job.

The other reason is that The Haemophilia Society itself has in this honour been given a formal and national recognition of the value of its work. Those who know him will need no telling that this second reason is the one that Ken Polton puts first.

J.R. Hunter
Honorary Chairman.

Among the letters of congratulation received were the following:-

From the President of The Haemophilia Society,
Sir Weldon Dalrymple-Champneys, Bt., C.B.

"My heartiest congratulations on your M.B.E. which I was delighted to see in the List this morning.
You have done wonderful work for The Haemophilia Society all these years and most of its success in building up has been due to you.
It is always refreshing to see work by someone so self-effacing as yourself rewarded.
I hope that the year so well begun will bring you much health and happiness."

From Michael Alison, Joint Parliamentary Under-Secretary of State,
Department of Health and Social Security.

"On behalf of the Secretary of State, and all other Ministers in the Department, I would like to offer sincere congratulations on your well deserved award of the M.B.E. in the New Year Honours List."

From Sir Philip Rogers, Permanent Under-Secretary of State.

"May I, on behalf of my colleagues in the Department, as well as myself, offer you warm congratulations on the appearance of your name in the New Year Honours List.
We are all pleased that your fine work for haemophiliacs has been recognized in this way."

- - - - - - - - - - - - - - - - - -

EDITORIAL

The start of 1972 prompts us to recall that it is now 20 years since it was discovered that some patients, thought until then to be haemophiliacs, were not in fact short of the anti-haemophilic factor (Factor VIII), but lacked another, later described as Factor IX.

The discovery was made simultaneously in the United States of America and in the United Kingdom where a paper, written by Dr. Rosemary Biggs and her colleagues, was published in the British Medical Journal under the heading, "Christmas Disease - a Condition Previously Mistaken for Haemophilia".

Since 1952 the impetus of progress in the field of haemophilia has increased. The function of the Haemophilia Centres has been extended so that they are now designated as Diagnostic and Treatment Centres instead of only Diagnostic and Registration Centres. Techniques of intravenous treatment have greatly improved as has the quality and production of materials. Probably the most important and significant advance was the discovery, in 1964, by Dr. Judith Pool and her colleagues at Stanford University School of Medicine, California, of cryoprecipitate - a material rich in Factor VIII. This is probably the most widely used of the blood products now available and has completely changed the lives of many haemophiliacs.

Progress and the demand for treatment have, in themselves, brought problems. There is still a shortage of money for staff and equipment but, perhaps most important, there is also a shortage of blood. To ease the burden upon the Blood Transfusion Service some hospitals now produce their own cryoprecipitate but, despite this, it has been found necessary in some places to restrict its use to patients under the age of 10 years. Also, it appears, there are still a number of haemophiliacs who are not being actively encouraged to attend hospital promptly if they think they are bleeding into a joint or muscle. In this connection we ask how many haemophiliacs have not yet been issued with the Department of Health booklet, "Notes on the Care of Patients with Hereditary Disorders", as well as full instructions as to who to telephone, night or day, at their Haemophilia Centre, when they are in trouble?

Some idea of the increase in the problem is given in figures published recently by the Oxford Haemophilia Centre. In 1968, 11,954 blood donations were used to treat haemophiliacs at Oxford. In 1969 the figure had risen to 13,373, and in 1970, 16,994. This last figure represents about one quarter of the total blood collected by the Oxford Regional Blood Transfusion Centre and was used to treat 220 patients, one quarter of the haemophiliacs registered at Oxford. A number of doctors suggest that regular infusions should be given to avoid frequent bleeding episodes but, if 1,000 haemophiliacs were to attend hospital for twice weekly doses of cryoprecipitate prepared from 10 donor units of blood, it would mean that one million blood donations will be required each year just for this purpose.

The total number of donations dealt with annually by the National Blood Transfusion Service throughout the country is just over 1¼ million, this from a population of over 55 million people. The Blood Transfusion Service is obviously finding it difficult to cope with the enormous increase in the demand for blood and although an increase in the number of donors appears to be the obvious answer, to put this into practice will not be very easy.

Through its Research Fund the Haemophilia Society has been able to help some of the Haemophilia Centres and during the coming year, in accordance with our aim of helping all haemophiliacs either directly or indirectly, we will be looking to see if there is any way in which we can help the Blood Transfusion Service. There may be flaws in the Service and, indeed, in the National Health Service as a whole but, as a group, haemophiliacs in the

/United Kingdom

United Kingdom have good reason to be grateful for the present system compared with many other countries. The following editorial reprinted from "The Practitioner" emphasises this view:

> "Our National Blood Transfusion Service is the envy of the world and a magnificent tribute to the spirit of voluntary service that still pervades this island home of ours in spite of the inroads of bureaucracy. In 1969, in England and Wales, 1,364,591 donors provided 1,302,907 bottles of blood, each containing ¾ pint (415 ml.). The surgeons may still be unsatisfied, but if they were only to look west across the Atlantic they would very quickly learn to be grateful for the service that the voluntary blood donors provide for them. It might also persuade them to be a little more careful in their use of this life-saving fluid.
>
> In the United States of America, commercial blood banks are a major source of blood and, according to J. Garrott Allen (Ann. Surg., 1970, 172, 927), they offer 'a substantially inferior product than the blood bank whose source depends entirely on volunteer donors'. He quotes two different sets of figures of the incidence of serum hepatitis following open heart surgery, depending upon whether commercial or voluntary blood was used. In the two groups the incidence of serum hepatitis with commercial blood was 31 and 51 per cent., compared with no cases with voluntary blood in either group. In view of the sources of commercial blood these figures are scarcely surprising. According to Allen, 'contributors to commercial banks appear to be related to three distinct populations; (1) prison donors, (2) Skid-Row donors, and (3) chronic addict donors'. 'Unfortunately', he comments in a pleasingly magnificent understatement, 'the incentive for these individuals to sell their blood is very great. The prisoner often has no other source of income. The Skid-Row donor is generally unemployed, and the chronic addict donor is in need of money to satisfy his drug addiction.' If this is what private enterprise in medicine means, then there is a lot to be said for our National Health Service."

- - - - - - - - - -

Footnote: In an effort to recruit blood donors a cinema in Seattle, U.S.A. gave a free ticket to anyone volunteering to give a pint of blood. The film being showm was "Dracula".

- - - - - - - - - -

ANNUAL SUBSCRIPTIONS

Annual Subscriptions were due on 1st January and we ask all members who have not already done so to forward their 25p as soon as possible.

As members will appreciate this does not cover the cost of the News Bulletins and other literature and a donation will, therefore, be much appreciated. Such a donation can be greatly increased by means of a Deed of Covenant and the Treasurer will be pleased to send details to any member, upon request.

- - - - - - - - - -

INSURANCE

As members will know the Haemophilia Society has been appointed agents to a firm of Insurance Brokers. Enquiries and requests for information should be sent to Mr. D. Rosenblatt, Executive Consultant, Vincent Wallace & Co., 233 High Street, Waltham Cross, Herts. (Tel. Waltham Cross 31971). It must be understood that each individual case will be considered strictly on its own merits.

- - - - - - - - - -

NOT RELEVANT

SOUTH WALES GROUP (CARDIFF)

The Group continues to flourish and recent activities include a White Elephant Stall and Coconut Shy at the St. Mellons Agricultural Show, a Fashion Show at Cardiff City Hall, a Social Evening at Llandaff Rugby Club, and a Wine and Cheese Evening at the Royal College of Nursing, Heath.

On the 24th December, a party of 30 children went to the pantomime "Dick Whittington", in Cardiff.

The Group has sent a cheque for £500 towards the Society's Research Appeal, with the request that it be used to support the work of Dr. A.L. Bloom, Director of the Haemophilia Centre at Cardiff Royal Infirmary. The money will be used to purchase essential pieces of research equipment.

- - - - - - - - -

NOT RELEVANT

NOT RELEVANT

ITV APPEAL

An appeal on behalf of the Society, to raise funds for Haemophilia Research, will be made on ITV at 7 p.m. on Sunday, 27th February 1972 by the distinguished actor Mr. Kenneth More.

A sheet of printed, gummed labels are enclosed which we hope you will fix to letters etc., to give the appeal maximum publicity. If you know of anyone who might be interested why not stick one on a post card and send it to them.

Further sheets will be sent on request.

CHRISTMAS CARDS

Grateful thanks go to all who sold Christmas Cards on behalf of the Society. We anticipate that 1971 will be a record year and to assist us in finalising our accounts we ask if all those who have not yet paid for their cards will please do so as soon as possible.

- - - - - - - - - -

B.B.C. "Week's Good Cause" Appeal.

The appeal, made by the popular radio and T.V. personality, Mr. Jimmy Savile, on 12th December, brought donations ranging from a 3p stamp to a cheque for £500. Money is still being received and the total to date is £1,011, the most we have ever received from a radio appeal.

- - - - - - - - - -

ANNUAL GENERAL MEETING

The Annual General Meeting of the Society will take place on the afternoon of Sunday, 30th April, 1972, at Lewisham Hospital, London, S.E.13.

A formal notice will be sent to all members in due course.

- - - - - - - - - -

NOT RELEVANT

- - - - - - - - - -

BALL PENS

Ball pens are always available priced at 6 p each, or for £3.00 we can supply 50 pens in an acetate display drum with price label. The pens are produced in smart red and black case colours and are engraved, in silver lettering, "HAEMOPHILIA RESEARCH".

- - - - - - - - - -

REPORT on the 1st EUROPEAN (REGIONAL) MEETING of the WORLD FEDERATION OF HEMOPHILIA - held in MILAN on 13th SEPTEMBER, 1971.

SPONSORED by the WORLD HEALTH ORGANISATION.

The meeting was divided into three sections.

1. Medical Session concerning the distribution and availability of therapeutic treatment.
2. Social Legislation.
3. The Haemophiliac at Work.

The meeting was opened by the President of the World Federation, Mr. Frank Schnabel, who was concerned with the role of Europe in WFH matters at the international level. He suggested there should be a "Marshall Plan" for haemophiliacs in the third world.

The World Health Organisation representative spoke briefly on the international possibilities of co-operation on problems such as diagnosis, research, the identification of carriers, etc., and gave as the major objective "the ability to guarantee a long, happy, and productive life to haemophiliacs".

Session 1. This session was largely concerned with the distribution of cryoprecipitate, both extant and planned. The session contained a high proportion of technical papers which, while interesting, were of more benefit to the professional members of the audience. The papers did show, however, how very diverse is the pattern of treatment, even within Europe. The session raised the general question of whether to centralise medical facilities or attempt to distribute them more evenly, (geographically).

Session 2. This session was, in fact, a detailed account of the State Welfare facilities available to member countries. It revealed, as did Session 1, the great variation in Social Welfare schemes as they affect haemophiliacs within Europe. Whereas many countries had an existing framework of legislation it was quite clear that great pressure was frequently required to make the responsible authorities operate it.

Session 3. This session was Chaired by the Reverend Alan Tanner. His introductory theme was the value of work as an agent in giving a man self respect and confidence for life. He emphasised the supportive role that the parents of haemophiliacs, social workers, and doctors, had to play in the crucial years of a boy's development. This role was vital in enabling a boy to become "a whole man" - capable of forming normal relationships and taking work in his stride, as a normal part of "the full life".

A great variety of other topics were raised in this session but almost all revealed a common theme - i.e. that improvements in medical treatment and its increasing availability far from ending the problems which haemophiliacs face, in fact, create new problems and new challenges. A normal or quasi-normal life is now possible if new techniques of support and a more integrated effort, on the part of parents, doctors, and social workers, can be applied to the psychological problems of the haemophiliac in the crucial formative years of childhood and adolescence.

Shortly after the meeting the following letter was received from a doctor, one of the leading authorities in this country on haemophilia.

> "I recently attended the meeting in Milan, as you possibly know. I enjoyed meeting the enthusiastic members of your organisation in the United Kingdom as well as getting a wider scope of knowledge from the various international representatives. All in the British Centres seem to be as far ahead as those in other countries and certainly further ahead than some.
>
> It seems to me that the treatment of haemophilia is going to become increasingly complex and that some additional hospital staff in both the medical and technical spheres is long overdue.
>
> It is disappointing that no additional funds have been set aside for the very worth while job of preventing relatively young patients from getting crippling deformities. So far as our Haemophilia Centre is concerned the only additional member of staff to cover quite an active service has been a junior trainee technician in the Department of Pathology, who is paid for by our Research Committee".

The Eighth Congress of the World Federation of Hemophilia is to be held in Buenos Aires - 24th to 27th July 1972.

Thos. Cook and Sons have prepared two itineraries, one covering a week and the other a fortnight. Unfortunately, for various reasons, no special air fares are in operation to South America, and based upon normal economy class return air fares the cost of the one week trip including hotel (room only) will be in the region of £420. The two week trip on a similar basis will cost about £470.

Full details can be obtained from:-

Thos. Cook & Son Ltd.,
Conference Booking Service,
Reference CBS/W,
45, Berkeley Street,
London, W1A 1EB

NOT RELEVANT