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The Bulletin

Patron, H.R.H. The Duchess of Kent

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THE HAEMOPHILIA SOCIETY

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THE CHAIRMAN WRITES . . .

I am glad to be given this opportunity of writing to you all and I hope that the invitation will be repeated from time to time as there are many matters which I would like to share with you.

For the moment, I shall concentrate on one point and draw your attention to the 'facts' set out above.

It is a matter of principle that we do not remove anyone's name from the mailing list, unless we are particularly asked to do so, but, of course, this does mean that we run the risk of sending communications to people who no longer wish to receive them and we can never be certain about the real level of active membership.

It is very important that, if you wish to retain your membership of the Society, you send your annual subscription of one pound or, if you are a haemophiliac and cannot afford that amount, write to tell us so that you may still retain full membership without making any contribution.

I need hardly add that the one pound subscription is itself a token sum, contributed towards the cost of producing the Bulletin and its postage, quite apart from our other publications and materials available to members.

It will help us greatly and reduce our administrative costs if you will renew your subscription for 1982 as speedily as possible. If you are in a position to do so, an additional donation would be most welcome — especially if made under a Deed of Covenant, in connection with which we enclose our new easy-to-understand leaflet.

With all good wishes for 1982.

*The Rev. Alan J. Tanner MA
Chairman*

FACTS:

(1) **ANNUAL SUBSCRIPTIONS ARE NOW DUE** — a form for renewal of your annual membership of the Society is enclosed with this Bulletin.

(2) **MEMBERSHIP COSTS £1.00** each year. In cases of hardship, free membership is available to haemophiliacs — again, this has to be applied for annually if you wish to remain a full member of the Society.

(3) In 1981 **LESS THAN 50% of those on our mailing list** actually paid membership fees or applied for free membership!

PRESIDENT

At the November 1981 meeting of the Council of the Society it was unanimously agreed to invite Professor R. G. Macfarlane to become President, the office having been vacant since the death of Sir Weldon Dalrymple-Champneys a year ago.

We are delighted that Professor Macfarlane has agreed to accept our invitation, thus maintaining the continuity of our having an eminent member of the medical profession as our President for the past 25 years.

Professor Macfarlane, whose career commenced at St. Bartholomew's Hospital, London, in 1933, is known throughout the world as the man who established Oxford as a most important centre for all aspects of research and the treatment of haemophilia. We still have in our files a letter from him, written in 1952, telling us of the work being done on increasing the precision of diagnosis, the possibility of detecting female carriers, trying to isolate the clotting defect, and the production of an efficient therapy. At



Professor R. G. Macfarlane

that time, for most of us these were dreams for the future. Also mentioned is "a condition closely resembling haemophilia, which has hitherto been mistaken for it and may account for some of the failures to respond to treatment." This, of course, refers to Factor IX deficiency (Christmas disease) which was the subject of a paper published in the British Medical Journal issue of 27th December 1952, written by Professor Macfarlane and his co-workers.

We are, obviously, extremely fortunate in having as our President a man who has always supported and encouraged the work of the Society and of whom it has been written "there is no one who has contributed more to the understanding of haemophilia and those suffering from it. His logical and scientific approach often showed the mark of genius."

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Rev. A. Tanner MA K. Polton MBE

C. Knight BA (Editor)

K. Milne, BSc (Assistant Editor)

A NEW GROUP

The Society welcomes a new Group in Birmingham . . . THE LADYWOOD GROUP was recently accepted into the Society. The Group is based on the Birmingham Children's Hospital and will be of particular interest to the parents of children who have haemophilia. The contact person is Sister Gregory, whose work telephone number is:

GRO-C and ask for
Haemophilia Centre.

ADMINISTRATION OF FACTOR VIII BY MOUTH — HOPE & REALITY

D. E. G. Austen and C. R. Rizza,
Oxford Haemophilia Centre,
Churchill Hospital, Oxford

The blood clotting and haemostatic defect of classical haemophilia (Haemophilia A factor VIII deficiency) is due to a deficiency of factor VIII clotting activity which is associated with a large plasma glycoprotein. Treatment of the condition at present consists of replacing the missing factor by means of intravenous transfusions of blood products rich in factor VIII. This form of treatment is very effective in controlling bleeding whether it be following injury or major surgery and most patients find the venepuncture only a minor disadvantage compared with the benefits they gain. It goes without saying, however, that if administration of the factor by another more convenient route could be shown to be effective this would be an important advance in treatment. The oral route is the easiest, commonest and safest route of drug administration. Disadvantages to this route of administration include destruction of some drugs by acids or digestive enzymes and irregular absorption in the presence of food. Unfortunately since factor VIII is a protein and the activity is labile, it is presumably digested in the stomach and small intestine in the same way as any other protein we eat. The stomach in particular secretes powerful acids and enzymes which attack proteins so that if there is to be any likelihood of administering factor VIII by mouth it must be in some way protected from the effects of digestive enzymes. It would be interesting to know however what would happen if factor VIII could be so allowed to enter the small intestine where the environment might be less unfriendly to factor VIII and where it might be absorbed along with the other proteins, fat and carbohydrates. Enclosing the factor in gelatin capsules designed to release the contents in the small intestine might be a possible method of protecting the factor but as far as we are aware this has not been studied. Another method of possibly achieving protection for the factor has been under much investigation recently and that is to enclose the factor VIII within liposomes. Briefly, liposomes are small balloon-like structures, a few microns in diameter, made up of concentric layers of lipoprotein (fat). On cross-section under the microscope they look rather like an onion which has been cut across. Within this balloon of fat, in between the layers of the lipoprotein or in the central cavity, it is possible to encapsulate a variety of drugs and enzymes. This has been achieved successfully with substances such as insulin and it has been shown that when liposomes containing insulin were fed to diabetic rats by mouth the sugar in the rat's blood fell and it was presumed that the insulin had entered the animal's bloodstream. It seemed therefore very reasonable to try to incorporate factor VIII into liposomes especially since factor VIII has a strong tendency to bind to lipid substances. Dr. Hemker and his colleagues (1980) in

TABLE

Material	Subject	No. of experiments	Units of factor VIII	Result
Factor VIII and chylomicra	Haemophiliac	1	2294	Negative
Factor VIII in water and oil emulsion	Haemophiliac	2	1000	Negative
Factor VIII in liposomes	Rabbit	1	18*	Negative
Factor VIII on positively charged liposomes	Rabbit	1	123*	Negative
Factor IX in liposomes	Christmas disease patient	1	166	Negative

* N.B. Values for human factor VIII-related antigen. Coagulant activity was a third of these levels

Holland have recently reported on some extremely interesting experiments in which they administered liposomes containing factor VIII to a severely affected haemophiliac and found that the patient's factor VIII level rose to approximately 7% of normal after 30 minutes and remained elevated for at least 50 hours. The persistent elevation of factor VIII for more than 2 days was particularly interesting since it suggested that an oral dose of liposome-factor VIII three to four times a week might change a severely affected haemophiliac into a mildly affected one.

A slightly different approach to the problem has been made by another group of Dutch workers (Paulssen and van Pelt 1981). They too have made use of the tendency of factor VIII to bind to lipid. However, they did not prepare liposomes but encouraged the factor VIII to adhere to the surface of minute fat globules (Chylomicrons). When this material was given by mouth to a 22-month old mildly affected haemophiliac the level of factor VIII rose from 9% of normal to 15% of normal and again it was found that the level of factor VIII remained elevated above the base level for at least 24 hours. Those authors then went on to administer this preparation twice weekly over an 8 month period and factor VIII levels ranging from 12% to 22% of normal were found in the patient's blood. Even higher levels, 20–30% of normal, were achieved if the emulsion was given daily. This certainly seems an attractive way of administering factor VIII since the method of producing the factor VIII-fat mixture is relatively simple compared to that required for making liposomes.

Our own experiments at Oxford over the past 2 years into the possible use of liposomes or chylomicrons loaded with factor VIII or factor IX for treating haemophilia and Christmas disease have so far not met with the same success as that of the Dutch workers (Austen & Rizza 1981). Our experience is summarised in the table. This is obviously a very limited experience and much more work requires to be done to try to overcome some of the technical difficulties encountered in preparing factor VIII-

liposome preparations. As far as we can see the problems of preparing liposomes containing factor VIII are mainly three:—

First is the difficulty of obtaining a high encapsulation level of the factor. Often in liposome preparations less than 10% of the material becomes entrapped and therefore the supernatant factor VIII solution has to be treated repeatedly with successive additions of fresh liposomes to obtain enough material for a therapeutic dose and also to ensure economical use of factor VIII. The second problem is that liposomes were principally considered as drug carriers for intravenous infusions and accordingly they are not specifically structured to withstand the digestive enzymes of the gastrointestinal tract. Finally, the optimum conditions for liposome adsorption in the intestinal tract are not known nor indeed is the mechanism of absorption understood. There is some evidence to suggest that absorption can only occur when liposomes are below a certain critical size. If this is so then a homogeneous mixture of very small liposomes would be the objective. On the other hand if they are not adsorbed as whole liposomes but broken down and then reconstituted once the factor VIII has passed through the gut wall then the aim might be to deliver large liposomes intact to the intestinal wall and to allow them to release their contents there.

There is no doubt that work on this very important approach to treatment must continue. If the observations of either group of Dutch workers are confirmed by others and if the oral preparation can make economical use of factor VIII we can envisage a situation where severely affected haemophiliacs might be rendered mildly affected by twice or thrice weekly ingestion of factor VIII. For the treatment of severe bleeding or for major surgery the factor would of course still need to be administered intravenously. It would also be important to make sure that the ingestion of large amounts of fat over a long period of time were not harmful to the patients.

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MISCELLANY

**Joint Announcement by
British Technology Group and
Prutec Limited**

MAJOR INVESTMENT OF PUBLIC AND PRIVATE FINANCE IN BLOOD FRACTIONATION COMPANY

The British Technology Group (BTG) and PRUTEC Limited (a subsidiary company of the Prudential Assurance Company Limited) announce that they are to invest £4 million in Speywood Laboratories Limited, the British company with a worldwide-reputation in developing proteins from blood for medical use. BTG and PRUTEC will each take 25% of the Company's equity share holding.

This investment will enable Speywood to expand and accelerate its five-year R&D programme in the areas of blood fractionation and genetic engineering. Since the Company was formed, seven years ago, Speywood has succeeded in developing unique fractionation technologies. These technologies make possible the commercial production, at high yields, of very pure animal (porcine) and human blood proteins for use in replacement therapy.

The Company's newly commissioned 10,000 sq.ft. factory in Wrexham is currently fractionating 3000 litres of pig's blood every week and this will rise to

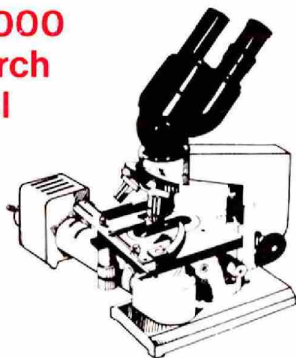
20,000 litres a week in two years' time. It is already producing a highly purified, therapeutic material for those haemophilic patients who react adversely to Factor VIII derived from human blood.

As part of the expanded R&D programme, a further 20,000 sq.ft. will be added to the existing factory. This will house extensive research facilities to enable Speywood to develop and produce other therapeutic blood proteins for the treatment of septicaemia, emphysema and cancer, and will include the first commercial human blood fractionation unit ever to be established in the United Kingdom.

Forming a major part of the Company's R&D programme is an investigation into the viability of genetically engineering blood proteins. A team has already been set up, comprising leading geneticists, technologists and clinicians, at Oxford and London Universities; AERE Harwell; The Royal Free and Royal Hallamshire hospitals in London and Sheffield.

David Heath, Managing Director and founder of Speywood Laboratories, said today: "We are at a very exciting stage in our development and I'm delighted that our hard work over the last seven years has resulted in this support by BTG and PRUTEC. Not only will this extra investment create new jobs but it will add momentum to our existing lead in fractionation technology and bring nearer the exciting possibility of producing valuable blood proteins through genetic engineering. If this becomes a reality, as I have every confidence it will, then by the year 2001 we may never need to collect plasma from donors again."

£250,000 Research Appeal



We are now in the third year of our Research Appeal and thanks to the tremendous support given by our Groups and individual members we have now passed the halfway mark.

Since we first started making grants to hospitals we have allocated over £¼ million throughout the United Kingdom as shown in the following list.

Alton	Leeds
Bangor	Leicester
Belfast	Lincoln
Birmingham	London
Boscombe	Manchester
Brentwood	Margate
Cambridge	Newcastle
Cardiff	Northampton
Derby	Norwich
Dundee	Nottingham
Edinburgh	Oxford
Glasgow	Rhyl
Lancaster	Sheffield
Liverpool	Southampton

During the last year alone we have made grants in support of work on hepatitis, carrier detection, synthesis of Factor VIII, and to purchase equipment, such as auto-alarm freezers, photometers, all essential if the care and treatment of those with haemophilia and allied blood disorders is to be maintained.

It would be a marvellous achievement if we could reach our target of £250,000 by the end of 1982 and no better way of marking the 40th year since the existence of a haemophilia society in the United Kingdom was recorded.

40 years is a Ruby Anniversary and, whilst we do not expect to receive many gifts in that form, we assure all members that donations from 40 pence to 40 pounds will be received with equal gratitude.

Please do all you can to help the Society to meet the increasing number of requests for grants that we are receiving from those striving to attain the ultimate aim of us all, **A CURE FOR HAEMOPHILIA.**

THE ANNUAL DRAW: 1981

The Society's Annual Draw was held in Bristol on Saturday 17th October at a Cabaret Evening organised by the Bristol and South West Group.

Over 200 people attended this happy event on a stormy and wet evening and a good time was had by all.

The Society was represented by the

Honorary Secretary, Ken Polton, who was also the Draw organiser; Ken Milne; and the Co-ordinator, David Watters.

The Draw was made by Bob Hesford, Bristol and England Rugby International, who recently toured Argentina and has just been selected for England again this year.

Prizes have been distributed to the lucky winners.



*Ken Polton, Ken Milne and Bob Hesford
at the Annual Draw*

DR. L. KUTTNER RETIRES

Executive Committee member, Dr. Ludwig Kuttner, has relinquished the post of Group Liaison Officer, the duties of which he has performed with such marked success for 10 years.

It is due to his work that the number of our Groups has increased four-fold during that period. Dr. Kuttner's idea of holding regular meetings of Group Representatives has resulted in a tremendous upsurge of enthusiasm among Groups throughout the country from which all in the Society have derived great benefit.

At a recent Council Meeting the Honorary Chairman, the Rev. Alan Tanner, paid tribute to Dr. Kuttner and Mrs. Kuttner, who has also been a keen supporter of the Society since they first became members some 30 years ago. He referred to the debt of gratitude owed to them both and, amid prolonged applause, made a presentation of two antique candlesticks as a mark of appreciation from all members of the Society.



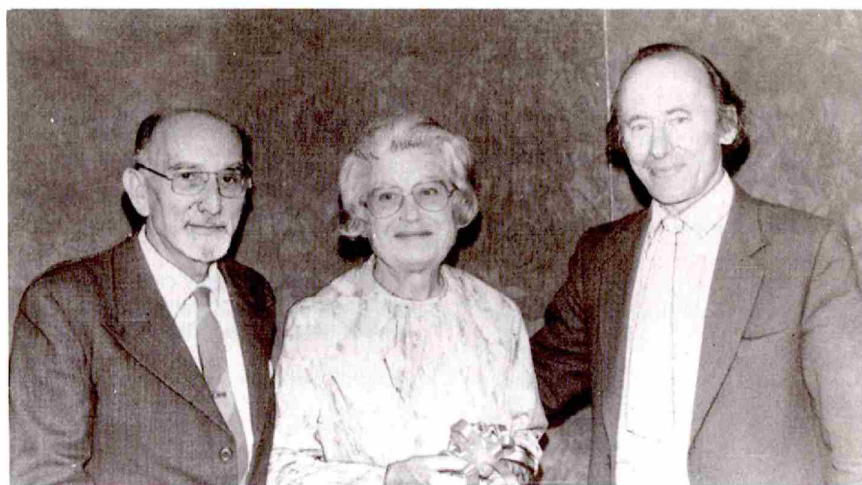
Dr. and Mrs. L. Kuttner

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R. G. MACFARLANE AWARD – 1980

The presentation of the R. G. Macfarlane Award for 1980 took place at a happy and informal event at the Royal Hallamshire Hospital, Sheffield on the evening of Thursday, 15th October. The recipient of the Award was Professor Edward Blackburn who recently retired as Director of the Sheffield Centre, having been associated with treatment of haemophiliacs in Sheffield since 1946.

In presenting the Award, the Rev. Alan Tanner, Chairman of the Haemophilia Society, outlined the history of the Award, made to recognise officially Professor Macfarlane's work in the study and management of haemophilia and to register the appreciation of the Society for the support given by him for many years. "The Award," he continued, "may be given to a doctor, scientist, or other person who has been involved in research, in the management of haemophilia, or in the more general care of those with haemophilia or related disorders, and tonight we are here to recognise the



Dr. and Mrs. Kuttner with Rev. A. Tanner

contribution of Professor Blackburn in those fields."

Professor Blackburn attended Morley Grammar School in Leeds and was the son of a schoolmaster. He won a scholarship to Cambridge but, because of his father's ill health, was unable to take this up. The Chairman remarked how this typified his care for people. Instead of going to Cambridge, he studied at Leeds University and arrived at Sheffield in 1946. The Court of Management of the Royal Infirmary Sheffield awarded a special, postgraduate scholarship which enabled him to spend two years working in London, Edinburgh, Glasgow and Oxford, where he was one of the earliest members of medical staff to be trained under Professor R. G. Macfarlane. During the late 1940's he had, along with Professor Macfarlane and Dr. John Wilkinson of Manchester, set up the first meetings of Haemophilia Centre Directors in the UK. This committee he served for 30 years, the last ten as Chairman. Eddie Blackburn was a campaigner for a national network of Centres and the fruits of this are now being reaped by patients in various Haemophilia Centres around the country.

Professor Blackburn is both a founder member and Fellow of the Royal College

of Pathologists and a Fellow of the Royal College of Physicians.

In 1970, in recognition of his special contribution to haematology, he was given a Personal Chair in Haematology at the University of Sheffield.

"On top of all this, however, Professor Blackburn had built up wonderful and caring relationships with his patients who held him in the very highest esteem, as proved by the large number of people present."

It was therefore with the greatest delight that the Society were now presenting the 1980 R. G. Macfarlane Award to Professor Blackburn.

The Rev. Alan Tanner proceeded to present the vellum which read:—

THE R. G. MACFARLANE AWARD 1980

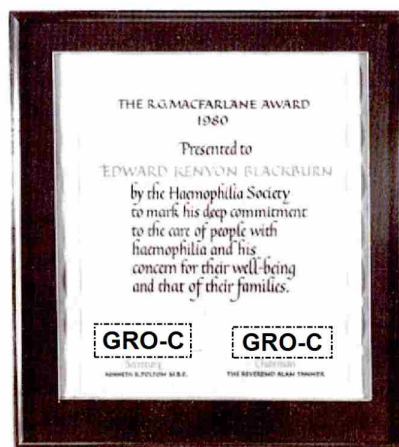
Presented to
EDWARD KENYON BLACKBURN
by the Haemophilia Society
to mark his deep commitment to
the care of people with haemophilia
and his concern for their well-being
and that of their families.

Amidst prolonged applause from the assembled company Professor Blackburn received the citation and the medal.

In his reply Professor Blackburn told of his interest in haemophilia and how he had been excited initially by the challenge of a young patient in the Royal Infirmary Sheffield. Things had moved a long way since those days but Professor Blackburn was still anxious to do further work on oral therapy before he finally gave up work. He paid tribute to his staff and all the patients, who he counted it a very great privilege to have worked with. His reply was warmly applauded.

A pleasant evening followed, during which a buffet supper was served and many old acquaintanceship renewed.

The Society's Executive Committee was represented by the Chairman, The Rev. Alan Tanner; the Vice-Chairman, J. R. Hunter; Mrs. Britten; and the Co-ordinator, David Watters.



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DR. BARNARDO'S CHAMPION CHILDREN OF THE YEAR AWARD

We are sure that all members will wish to join in congratulating **GRO-A** aged 14, who was awarded joint first place in the "TRIUMPH OVER ADVERSITY" category of the Dr. Barnardo's Champion Children of the Year.

The award was made by HRH Princess Margaret at a special luncheon held in London on 26th November 1981, the judge being **GRO-A** Britain's longest-surviving heart transplant patient.

GRO-A who lives in Brighton, was nominated by his school for his considerable achievements in sport, despite being severely affected by Christmas disease (Haemophilia B). In his early days he had a period of 5 years when he was, because of repeated, internal bleeding, almost continuously an in-patient at the Hospital for Sick Children, Great Ormond Street. His life has been transformed since he started on home treatment.

His perseverance and interest in sport led to his participation in swimming, shooting, football and athletics, but his main achievement has been in ski-ing for which he won a silver medal. For 3 years he has been to a ski school in the Italian Alps, chosen as it is not too far from the world famous Haemophilia Centre in Milan, run by Professor Pier Mannucci, with whom contact can be made if an emergency arises.

GRO-A award does, of course, recognise the selfless support given by his parents. **GRO-A** enthusiastic members of the Society and known to



many of us as founder-members of our Great Ormond Street and Sussex Groups.

We also congratulate **GRO-A** who has cystic fibrosis and **GRO-A** who has had a leg amputated because of cancer, on being joint winners of the award. The judge, **GRO-A**, who decided that all three should be winners summed up his feelings by saying, "How can I possibly pick one out of three such marvellous kids?"

Other categories of award covered Art, Music, Dancing, Drama, Sport, Mastermind, Superkids, and the judges were popular personalities such as **GRO-D**.

GRO-D

The entire afternoon was an exhilarating experience and the only pity felt by the Society's representative was that, in an age when many are quick to criticise the younger generation, the media, television and press, did not find it possible to give the event more coverage.



GRO-A

GRO-A and Princess Margaret

A NORTH WALES ADVENTURE

The North Wales Group of the Society sponsored a special, monitored, outdoor-pursuits course during the Spring Bank Holiday week in 1981. Taking part were ten young haemophiliacs and the base was Anglesey's Cornelyn Manor Activity and Study Centre. The holiday was all the more notable since, until very recently, such strenuous, adventure holidays would have been thought out of the question for young haemophiliacs. It is thanks to the pioneering spirit of Dr. Tom Korn, consultant haematologist from Bangor Hospital that ten boys aged between 10 and 16 years, from all over the country, were able to come together and have this taste of freedom and adventure in Anglesey.

Every precaution was taken to protect the boys from damage. A nurse was in 24 hour attendance and slept at the Centre, and both Dr. Korn and Dr. Huw Parry accompanied every activity.

Dr. Korn had previously written to each boy's doctor for their medical records and was familiar with their bleeding patterns and their weakest joints. This enabled him to administer a prophylactic treatment each morning before the day's programme began.

Despite the rain during the earlier part of the week a very full programme was completed. The week began with a visit to Beaumaris Castle on Sunday; a walk to Aber Waterfall on the Monday morning, followed by pony trekking at Llandegfan in the afternoon. On Tuesday the boys went canoeing on the rapids between the

GRO-A

GRO-A

lakes at Beddgelert and some of the boys attained levels of canoeing which non-haemophiliacs would have been proud to achieve.

Tuesday was spent fishing at Beaumaris and swimming at Llangefni pool. On Thursday the sun shone and dinghy sailing occupied the greater part of the day, while on Friday some went mountain walking while others had a trip in the Manor's own training yacht 'Sea Feather'.

Dr. Korn was absolutely delighted with the success of the holiday which exceeded his greatest expectations and gave him new hope for the future. "We hope this kind of activity-holiday can be repeated for similar groups of haemophiliacs. We want to prove to parents and children that they can live a normal life and achieve far more than they believed possible," said Dr. Korn.

And how did the young people react to the experience? "I hope there will be an opportunity to go again next year." "I did things like mountaineering, archery, sea-fishing which I had never done before." "The best holiday I have ever had, and the most active. I would like to go again if possible."

And the Mums and Dads? **GRO-A** arrived home yesterday... literally sparkling. The holiday has done him so much good. "It was a resounding success, he thoroughly enjoyed his week there: he was able to do things not normally available to him and he loved it."

The Society recognises the importance of adventure holidays like this for young haemophiliacs and we are most grateful to **GRO-A** of our North Wales Group for the initiative and hard work which they put into organising this holiday. **AND NOW IT'S HAPPENING AGAIN...** A number of places will be available during the week August 7th to 14th 1982. If you are interested please contact **GRO-A** IMMEDIATELY for fuller information. Places available are for boys between the ages of 8 and 16 years.

For details write **TODAY** to **GRO-A**
GRO-A **GRO-C**
GRO-C

BOXFILE

A LETTER FROM THE MINISTER



DEPARTMENT OF HEALTH AND SOCIAL SECURITY

I was very pleased to have had an opportunity to discuss the supply of Factor VIII with you and your colleagues from the Haemophilia Society on 21 October.

I appreciate your Society's concern about the extent to which the NHS relies upon commercial blood products. As I told you, the upgrading programme being carried out at the Blood Products Laboratory at Elstree will, at present yields, enable the Laboratory to double its output of Factor VIII to 30 million international units by the end of 1982. While this will not eliminate the need for commercial products, it represents a major step forward in NHS production of this vital material.

I also said that we plan to replace the existing Blood Products Laboratory within the next few years. Planning and design work have not yet progressed far enough for the capacity of the new plant to be decided, and it will depend on a number of considerations such as the extent to which the NHS is able to build up the supply of plasma. Although I endorse the principle of self-sufficiency in blood products, it is only realistic to recognise that demand for Factor VIII is constantly increasing, and that self-sufficiency is not a goal we can achieve in the immediate future.

May I say in conclusion how impressed I am by the excellent work which your Society does to further understanding of the problems which haemophilia can

cause. I think it would be very useful for us to meet again next year if you wish to review the supply of Factor VIII and other matters of interest to your members. I look forward to meeting you again.

Gerard Vaughan

DISABLED PERSONS RAILCARD

If you receive Attendance or Mobility Allowance, Private Car Allowance, have a DHSS car or three-wheeler, or receive Industrial Disablement Benefit, you may be entitled to a £10 Railcard which entitles you to travel on British Rail at half price.

Full details and application form are contained in a leaflet "Half price travel for the disabled" obtainable at most stations or British Rail offices.

JAUNDICE CASES SHOW UNEXPLAINED INCREASE

by Andrew Veitch

Figures released yesterday show that the number of cases of infective jaundice in England and Wales rose by 60 per cent to more than 5,000 last year, and the 5-14 year-olds suffered most.

The illness is commonly caused by one of the hepatitis viruses. There has been no reported increase of the severe hepatitis B version, so the evidence points to the comparatively mild hepatitis A. But this is on the decline — it is borne by faeces and depends on bad hygiene and bad water supplies.

"This is out of keeping with trends all over the world," Dame Sheila Sherlock, professor of medicine at the Royal Free Hospital, London, said yesterday. "I can't give any reason why young people are getting it."

The rate of jaundice among children has been falling for years, but last year it shot up: it is now at its highest point for four years, and 5-14 year-olds are suffering more than any other age group.

One possible culprit is a third virus, simply called hepatitis non-A non-B (because it is neither one nor the other). This is known to be spreading in the States, and there is speculation that it may have arrived here.

The figures from the Office of Population Censuses and Surveys show that there were 5,132 cases of infective jaundice last year, compared with 3,203 in 1979.

With grateful acknowledgements to the Editor of 'The Guardian', 5th August, 1981.

NEW YORK MARATHON

We reported in the last Bulletin that **GRO-D** successfully completed the New York Marathon. So please return your sponsorship forms and money as soon as possible. To date we have received almost £600 towards the Research Appeal... let's see if we can reward **GRO-D's** efforts by reaching £1,000!!!

N.B. Please send an addressed envelope if you require a receipt.

OBITUARY

It is with regret that we record the death, on 29th October 1981, of John Brodie, who will be remembered by many of our older members as the first Honorary Treasurer of the Society.

John was one of the small band of **GRO-C** who came together in the early 1940's to form the nucleus of the International Haemophilia Society. As a Senior Accountant at the Hospital for Sick Children, Great Ormond Street, he established a link which led to facilities being made available at the hospital which allowed us to hold some of the early Committee meetings there, general meetings in the Lecture Theatre, and later, Council Meetings in the Board Room. This also led to a succession of Medical Social Workers acting as advisers to the Society right up to the present time.

When he stood down from the office of Honorary Treasurer in 1952 John had established a sound financial basis on which the Society was able to build; he had participated in the drawing up of a constitution; and had taken the necessary steps to enable the Society to become a registered charity. He returned as an Executive Committee member in the 1960's, together with his wife Irene, a chartered physiotherapist, and his daughter Susan. Together, they gave valuable support during an extremely important period of the Society's development.

As Honorary Treasurer, John set an extremely high standard of efficiency and integrity, which those who have followed have endeavoured to match.

On behalf of all members we extend our sympathy to Mrs. Brodie and her family. We also thank those who sent donations to the Society in lieu of floral tributes.

WORLDWIDE

W.F.H. News

TRAVEL ABROAD

Travelling abroad for a haemophiliac for the first time can be a worrying thought and made me very sceptical as to whether or not it would be possible without encountering major problems. However, it turned out to be no problem at all.

First of all, may I introduce myself. My name is **GRO-A** and I am twenty-four years old. I have severe haemophilia but am fortunate not to have any physical deformities. I have been on home treatment for five years and both my girl-friend and I are experienced in preparation and administration of the therapy.

After spending all my holidays in the UK, we decided to go abroad for the first time this year. Our destination was Corfu, a picturesque island off the west coast of Greece. Although this island is not renowned for its medical facilities, it looked too attractive to miss, with crystal

clear seas, distinguished green mountains scattered with olive groves and, of course, the sun.

My first step towards the holiday was to approach my Haemophilia Centre in Sheffield to ask them if there was any reason why I should not travel overseas. They told me that, provided I did not have a serious bleed or develop inhibitors before leaving home, there would not be any problem. My next step was to approach the local DHSS for pamphlet SA.30 titled "Medical Treatment During Visits Abroad", which anyone travelling abroad is advised to read and complete. It outlines how to get urgent treatment during visits abroad free of charge, or at a reduced cost, providing the UK has a health agreement with your host country. These include both the European Economic Community and various other countries. At the end of the pamphlet is an application form (CM1) which is to be completed and submitted to the DHSS, which then forwards form E111 to be shown when in need of treatment abroad. Although there seemed to be a reasonable amount of cover given by these documents, I felt it to be imperative to have independent insurance for any private medical expenses incurred, as Health Care Schemes in some countries are not always adequate.

I now had the task of finding a company who would insure me. I was advised to telephone Mr. David Watters at the Haemophilia Society who put me in touch with Mr. D. Rosenblatt, a Director of insurance brokers Brookdale Brealey. Brookdale Brealey offer haemophiliacs insurance through Lloyds and Mr. Rosenblatt is an active member of the Haemophilia Society, which receives the commission from insurance thus obtained.

Mr. Rosenblatt sent me a proposal form which stated the scale of premium, which was determined by the number of days holiday, the destination, e.g. Europe, USA or worldwide and a choice of three gradations of cover. All medical, baggage and cancellation risks were taken into account. This insurance is also available to non-haemophiliacs at half the premium.

Once the transaction was completed, I received the Lloyds Certificate giving in-depth details and conditions of the policy.

Having settled the insurance, I decided to have a letter in Greek to carry on my person giving details of my name, age, medical condition and the treatment materials I would be carrying. Also mentioned in the letter was the volume of concentrate I should be given in the event of an emergency.

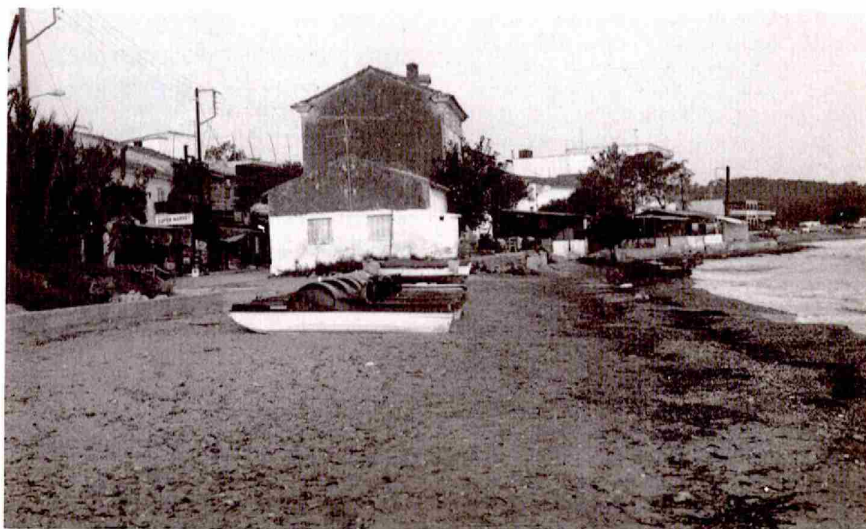
I located an interpreter in Sheffield, who kindly translated the letter into modern Greek. I felt that this letter would not only be an asset in explaining my medical condition, but also valuable if I was approached by the Greek Customs officials.

As the holiday drew closer, I started to gather together all the necessary documents which I was going to carry. These were the Green Haemophilia Card and the International Haemophilia Card - which I obtained from the Haemophilia Society in London and which provided personal medical information in four different languages. The Guide for Travelling Haemophiliacs which gives lists of countries where treatment is available and whom to contact. Other documents included the letter in Greek, DHSS form E111 and my passport which, fortunately I received from Liverpool, only a few days before flying, due to the strike which took place during 1981.

It is also advisable to write to the nearest centre to which you are spending your holiday and inform them that you are staying in their area, in case the need for treatment arises. The Guide for Travelling Haemophiliacs can be obtained from, or through, your local Centre or direct from the Society. Another valuable item to take on holiday is the Handbook for Home Therapy, both for personal reference, or in case someone inexperienced has to administer your treatment.

For transporting the concentrate, I used a small cooler-bag with two sealed Ice Packs. The sterile water and admin kit were securely packed in my suitcases. The cooler-bag was kept as hand luggage.

Finally, I included in my luggage enough bottles of concentrate for normal use, plus sufficient for use in an emergency. In the event of a broken limb, severe bleed, or any other emergency, I was advised by my Centre to give a specified



amount of concentrate and to get on the next possible flight home. The nearest Haemophilia Centre to Corfu was in Athens, on the Greek mainland, and because this was over two hours away by air, it was decided that it would be better this time in returning to England.

The morning we were to fly, we left Sheffield at 6.00 a.m. and arrived at Birmingham Airport at 7.30 a.m. Our flight was not due to leave until 9.45 a.m. but we had to be at the airport two hours before departure. After booking in, we went through Customs. I told the officer that I was carrying medical supplies and, surprisingly, he did not seem very interested. However, he told me to show the contents of the medical package to the airline official who inspected it by hand. Once she was satisfied with the contents, we went to the departure lounge and collected our Duty Free goods from the shop. Twenty minutes later, we boarded the plane for Corfu. The experience of taking off and landing was incredible and matched that of the holiday itself.

When we arrived at Corfu airport, no one challenged us about our luggage. We were taken by taxi to our holiday villa in Roda, which is situated on the northern part of the island. The distance between the airport and Roda village was about 18 miles, which seemed a long way as it was mid-day and the temperature was 90°C. We could not wait for an ice-cool drink and a swim.

Immediately we had unpacked, I examined the concentrate which, to my amazement, was still very cold after a six hour journey. I then put it in the fridge and the rest of the kit I kept in the wardrobe.

The first two days of the holiday passed without any problems. However, on the third day I woke with a bad bleed in my left knee, probably due to excessive swimming and dancing but within half an hour, my girlfriend and I had prepared a clean working surface to work on, laid out all the equipment required and given the infusion without any problems. Later that morning, we were escorted around the island by the owner of the villa who also doubles as a taxi driver. During the eight hour tour, I was constantly getting in and out of the car to photograph the delightful scenery and it was difficult for me to rest my leg.

This I paid for the following day, as there was little improvement. I then decided to have a second injection followed by plenty of rest on the beach. This did the trick and the following day I was back in good health. The rest of my holiday passed without any more bleeds and I was able to enjoy all that this enchanting island had to offer.

I was fortunate not to have had any need for state or private treatment whilst on holiday so I am unable to cast any light over this area. However, the thought of being thousands of miles from expert hands did not enter my mind and I would certainly recommend that any haemophiliac should go abroad, providing a certain amount of consideration is given to the trip beforehand.

GRO-A

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At the AGM of the North West Group, 25th October 1981, Mrs. **GRO-D** presented a cheque for £420 from a 26 mile marathon run to Chairman **GRO-A**

Mrs. **GRO-D** hoped it would be put towards Dr. Delamore's research into Inhibitors

MOBILITY ALLOWANCE

If you feel that the Society can help you with your application for Mobility Allowance or, if you have been turned down, with an appeal, please write to the Society's Co-ordinator, David Watters, giving full details.

STAMP CLUB

Mr. **GRO-D** runs the Stamp Club and his address has now changed to:

Mr. **GRO-D**
GRO-C

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GRO-D CHILDRENS
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DR PETER JONES: LIVING WITH HAEMOPHILIA — available to Society members (only) at the greatly reduced price of £6.00 including postage and packing.

This book has been translated into nine languages and is a treasure trove of useful information for haemophiliacs, their parents and relatives.

While there is no charge for any of the publications, apart from LIVING WITH HAEMOPHILIA, the Society welcomes donations to cover postal charges.