Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392202

1992 – No. 1

The Bulletin

Disability Living Allowance

NEWS ON BENEFITS

From April this year Attendance and Mobility Allowance will be combined into one benefit — Disability Living Allowance.

If you receive either or both allowances at present they will continue but will be paid as one benefit.

Disability Living Allowance will have two components.

There will be the CARE component (Attendance) payable at three different rates and the MOBILITY component payable at two different rates.

You may qualify for only one component or both. Emphasis will be placed on self-assessment by the claimant but we would urge you to obtain letters of support from your Centre and the Haemophilia Society.

Leaflets and claim packs are available from the Haemophilia Society or Social Security offices.

Disability Working Allowance is another new benefit for people with a disability who are already in work or about to start work. The objective of this allowance is to enable those with limited earning capacity to choose the work they could manage and top up their earnings with the allowance.

However, people already on benefits such as Invalidity Benefit may find they are no better off by working as this is a means tested benefit.

Notes on how people with haemophilia can claim the Disability Living Allowance are available from The Haemophilia Society — please write to GRO-A for further details. A fact sheet on the Disability Working Allowance is also available.

SWIM WITH DUNCAN GOODHEW

GRO-A

Throughout 1992 Bayer will be sponsoring a number of special swimming events for children with haemophilia. Duncan Goodhew will be there to help improve swimming techniques and emphasise the importance of swimming for young people with bleeding disorders.

The Society is delighted to be associated with these events which were launched at Newcastle on 11 January. Our picture shows Duncan in action with some of the lads and lasses of the North East.

Further details and entry forms will be available with the next issue of Update.

Arthur Bloom receives the RG Macfarlane Award

Professor Arthur Bloom, the Director of the Cardiff Haemophilia Centre, has been presented with the prestigious RG Macfarlane Award by The Haemophilia Society.

The presentation was made by the Chairman of The Haemophilia Society, Revd. Preb. Alan Tanner in gratitude for Professor Bloom's dedication to the care of people with haemophilia and von Willebrand's Syndrome. In particular, it was in recognition of the improvement in their quality of life through his research into diagnosis and treatment.

GRO-A the Chairman of the South Wales Group of The Haemophilia Society, commented upon the deep appreciation felt by all patients with haemophilia to Professor Bloom for his dedication and care.

The event took place at the University Hospital of Wales in Cardiff. In his speech of thanks Professor Bloom, with typical modesty, expressed the view that he was undeserving of the honour!

● **Revd. Preb. Alan Tanner, Chairman of the Haemophilia Society, presents the RG Macfarlane Award to Professor Bloom (centre), also in the picture is Mrs Bloom.**

THE HAEMOPHILIA SOCIETY

123 Westminster Bridge Road, London SE1 7HR

Tel: 071 928 2020
Fax: 071 620 1416

Registered Charity No. 288260

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Andy Cowe

Opinions expressed in The Bulletin do not necessarily reflect those of the Haemophilia Society

Together we can do great things

— by Andy Cowe Editor of The Bulletin

The Society's reputation and influence is frequently seen to exceed what might be expected from a small charity representing a rare medical condition.

In a list of UK national charities, the Haemophilia Society is 342nd in order of income. There are only five full-time and four part-time staff. Twelve elected volunteers guide its affairs, supported by three meetings of the council each year.

As a small organisation we achieve so much. In 1991 we won the right to be involved in the rewriting of the Department of Health guidelines for the treatment of haemophilia in the UK. This followed a long line of meetings between the Society and successive Secretaries of State for Health. This is a privilege not accorded to many bodies and clearly marks our standing.

As a charity we enjoy the active involvement of many eminent health care professionals who willingly give their valuable time to a society that is set up to benefit patients — not the medical profession. We are privileged to have their support.

Financial assistance is received from many sources, not least the blood products industry. Yet members of the Society are not direct purchasers of their products. Commercial sponsorship is not easily won and must be used wisely.

Support from the medical profession, sponsors and the huge number of other well wishers is deeply appreciated. As we enter 1992 we take this opportunity to thank you all. Your support allows us to achieve our goal — to improve the quality of life for people with haemophilia and their families.

Indeed, this common theme unites all those who support the Society. One of the distinctive features of the Haemophilia Society is the extent to which it is supported by those who are directly affected by the condition, personally or in the family.

Over the years dedicated voluntary groups have built the Society into the mature, respected organisation we see today. In local Groups, members provide contact, advice and encouragement and share the joys and sadness of one anothers lives. In Council and on the Executive Committee, members guide the Society through good times and bad. In the last decade the dedicated professional staff have provided special expertise in all areas of the Society's life.

Naturally, there is always a need for more people to become involved in our work. Some local Groups are desperately short of helpers. At regional and national level the need is always there for people with ability and enthusiasm to contribute to the Society's development.

If you have been helped by the Society, if you have something to offer other people with haemophilia (from sharing experiences to organising events) why not consider going along to a local Group meeting or playing a part in the life of the Society? Together we can do great things.

In this issue:

Extract from the 'News Bulletin' of September 1953

HAEMOTOLOGY CONGRESS 1953 AMSTERDAM

NEWS BULLETIN

The Congress is being held this year, September 8th to 12th, at Amsterdam.

The committee decided the Society should be represented so that we could have the benefit of first hand information, also a close liaison between the delegate for the Society and the Doctors there.

We understand Dr. Macfarlane and Dr. Dacie are reading papers there. They have agreed to assist our delegates as much as possible.

There will, we hope, also be an opportunity for Miss GRO-A to visit Professor Van Crebeld's Haemophilia Clinic whilst she is in Amsterdam. A Report will be sent to all members in due course. Our thanks must be given to Miss GRO-D for agreeing to attend the Conference on our behalf.

NOT RELEVANT

PROPHYLAXIS: THE NEXT STEP FORWARD?

By Charles Hay, Consultant Haematologist,
Director Regional Haemophilia Centre

INTRODUCTION

Prophylaxis is defined as treatment to prevent the development of disease. The prophylactic treatment of severe haemophilia involves factor VIII replacement therapy of sufficient frequency and dosage that spontaneous bleeding is prevented. This contrasts with the more commonly practiced "treatment on demand" where bleeds are treated as they arise.

Most patients with severe haemophilia continue to treat themselves in this manner when they develop a bleed. Prompt treatment greatly reduces joint damage. Most young patients without inhibitors, treated in this way, develop only one or two significant target joints and enjoy a good quality of life. Few reach adulthood with perfect joints, however, and these abnormal joints will usually become arthritic by middle life.

Short or long-term factor VIII or IX prophylaxis may be most useful in minimising or preventing this target bleeding. Prophylaxis has been used to a limited extent in patients with severe haemophilia since the late nineteen-seventies. Although it fell into disuse with the advent of HIV, prophylactic replacement therapy has been used more widely again since safe virally-inactivated concentrates became available.

SHORT TERM PROPHYLAXIS

Effective prophylactic factor VIII or IX replacement therapy maintains the patient's factor VIII or IX level above 2-5% at all times, thus preventing spontaneous joint bleeding and bleeding associated with strenuous exercise or intensive physiotherapy. This level of replacement will not prevent abnormal bleeding with trauma since the patient still has factor VIII or IX levels in the "moderate haemophilia" range.

Prophylactic treatment may allow target joints to settle completely if begun early in childhood before permanent joint damage has taken place. More commonly, especially in adults, the target joint is already mildly or moderately arthritic. In this situation a period of bleed-free prophylaxis combined with physiotherapy and exercise may, when the patient reverts to treatment on demand, improve muscle strength, reduce joint pain and bleeding frequency. It will not restore a joint to normal or prevent the ultimate long-term onset of osteoarthritis in the affected joints no matter how long prophylaxis continues.

Short-term prophylaxis is most commonly used to permit intensive physiotherapy and/or the resumption of regular exercise, and to help a troublesome target joint to settle. This usually continues for three to six months or longer, until the joint appears to have settled as much as it is likely to. Prophylaxis may also be used to cover special or stressful events such as examinations or job interviews where bleeds may be more frequent and most inconvenient. Many patients report an increased bleeding tendency at times of increased stress and conversely, a reduced tendency to bleed whilst on holiday.

Short-term prophylaxis is a useful adjunct to treatment on demand, and judiciously used during childhood can further reduce the development of target joints so that some adolescents grow up with essentially normal joints. Despite this, most sustain some joint damage and will ultimately develop osteoarthritis in one or more joints. Several groups, particularly those of Prof L. Aledort in New York, and Prof IM Nilson in Malmo, have investigated longer-term prophylaxis over the past few years in an attempt to reduce joint damage further.

LONG TERM PROPHYLAXIS

Prof Aledort and Prof IM Nilson aimed to start long-term prophylaxis as early as possible, often during the first six to 12 months of life and to continue this until at least the 18th birthday.

Again, the treatment aimed to maintain the patient's factor VIII level above 2-5% and thus prevent spontaneous bleeding during the years of the greatest bleeding frequency. Haemarthroses are most frequent when the patient is still growing becoming less frequent in early adulthood. Patients may be offered the option of changing to treatment on demand at the age of 18-20 years and about half of Prof Aledort's patients chose to make this change. These patients were followed up for at least five years, and in

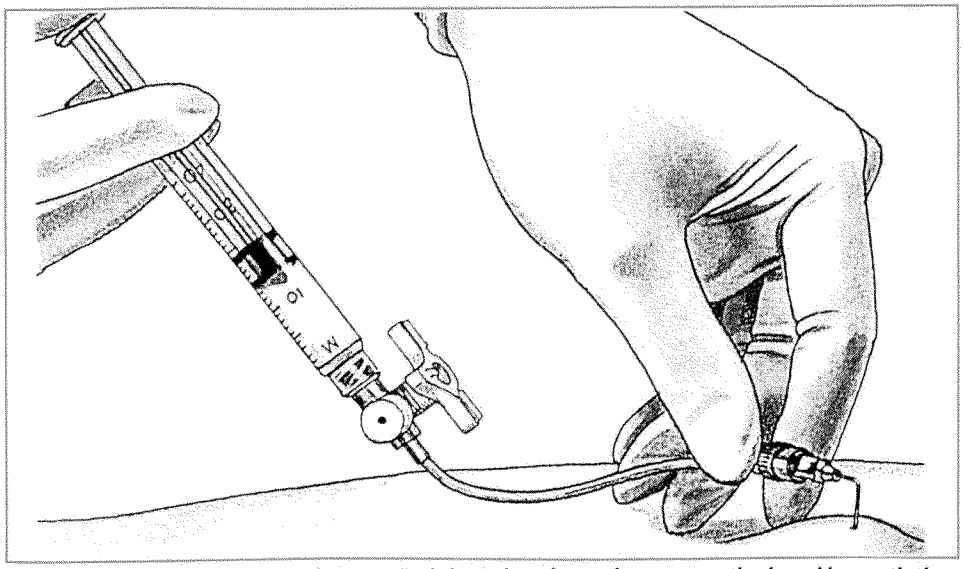


Fig.1. Schematic illustration of drug administration through a portacath placed beneath the skin of the chest wall.

most cases longer.

The preliminary results suggest that long-term prophylaxis, begun early in life, can prevent haemophilic joint damage altogether and permit a normal quality of life in the majority of patients with severe haemophilia who lack factor VIII inhibitors.

DOSAGE AND ADMINISTRATION

The dose required to maintain a factor VIII/IX level above 2-5% and prevent spontaneous bleeding varies from patient to patient according to age, size and factor VIII/IX half-life (which also varies to some extent).

The minimum dose required to prevent spontaneous bleeding appears to be about 1500 units of factor VIII per Kg. of bodyweight per year, although larger doses have been used by the Swedish group. This is most commonly given as 250-1000 units factor VIII three times a week or 600-1200 units factor IX twice weekly, according to body weight. Patients with established and troublesome target joints may require more frequent treatment at first.

Problems with venous access caused by the frequent injections are uncommon in adults but are an almost universal problem in small infants treated with this regime. This problem can be avoided to a large extent by the insertion of a central venous line of the "portacath" type (Fig 1).

This is a permanent indwelling catheter consisting of a small stainless steel chamber placed beneath the skin of the chest wall, into which the factor VIII or IX may be injected. This is connected by a catheter which passes under the skin to a major blood vessel. Portacaths are inserted during a short operation under general anaesthetic and, in the absence of complications, may remain in place and in use for a period of several years before surgical removal.

An alternative approach occasionally used in adults is the creation of an arteriovenous fistula. This requires a small operation in which an artery, usually in the forearm, is connected to a nearby vein. This greatly increases the blood flow through the vein so that over a period of weeks the vein becomes much more prominent and easier to use to give concentrate.

Prophylaxis should probably start by the age of three, although this is likely to vary from patient to patient. The most appropriate criteria for patient selection are not known. This issue is currently being considered by a working party of the UK haemophilia directors.

PROBLEMS WITH PROPHYLAXIS

Why is prophylactic replacement therapy not more widely used?

The reasons are various, and I present them in no particular order.

Most patients are adults with established arthropathy who bleed less frequently than children or adolescents and are likely to do just as well with treatment on demand, punctuated perhaps by periods of short-term prophylaxis and physiotherapy.

Prophylaxis may be unsuitable for some patients lacking parental support. Patients with inhibitors cannot readily be treated prophylactically unless inhibitors disappear following "desensitisation".

Portacaths may become infected or blocked in time, and then must be removed and replaced. Although infection is very much less of a problem in patients with haemophilia than amongst those with leukaemia, infection is nevertheless a potential problem of which every patient considering prophylaxis should be aware.

Finally the cost and supply of factor VIII concentrate may be a problem. Supply would have to be increased if prophylaxis became more widely practiced. The cost of prophylactic replacement therapy may be at least twice that of treatment on demand.

This increased cost must be balanced against the improvement in the quality of life both of the patient and their family, the patient's increased likelihood of finding employment and the long-term benefit to society as a whole. It is also likely that although the cost of such treatment will be greater during childhood, that such patients will bleed and cost less as adults if they revert to treatment on demand. They are also less likely to require joint replacement in middle life.

CONCLUSION

Prophylactic replacement therapy is a useful adjunct to treatment "on demand" in adults with severe haemophilia. Long-term prophylaxis appears to have only a small part to play in the management of adult haemophilia at the present time but is likely to replace treatment on demand in a significant proportion of children over the next few years.

NOT RELEVANT

NOT RELEVANT

NOT RELEVANT

PARENTS' CORNER

● **Thank you for the response we had to this page last Bulletin. We are pleased to know it is helping and also stirring others to write and share their experiences. You never know, what has happened to you might just be what someone else needs to read. This time we have one mum's account of how prophylaxis has changed her family's life and one mum who was helped last time. This is an encouragement to us to keep this page going.**

How about suggestions for holidays or short breaks? Is there somewhere you have been that you would recommend? Has anyone else any more stories like last time's Humpty Dumpty one —(wasn't it good?) or anything else that might be suitable.

● My son is eight years old and up until four months ago had, on average one bleed a fortnight. The majority were to his right knee and consequently it became frequently painful and irreversibly damaged. His doctor at the Haemophilia Centre advised that we begin prophylaxis to prevent further damage and eliminate future bleeds.

Initially it took time to adjust, but since we found a routine, things have improved immensely. My son has had no further bleeds, I am no longer on edge waiting for the school to phone and he seems more contented (probably because I nag him less — "be careful", "you can't do this!", "don't do that!").

His knee is in better shape now, free from pain and hopefully free from further bleeding episodes.
Mrs GRO-A

● **On the Letter Page of the November Bulletin recently received, one letter brought me some consolation, and that was one from** GRO-A **and family' of Hastings.**

The reason that I have chosen to write to you is that I can totally sympathise with this lady, who suffered for some 40 years before being diagnosed as having von Willebrand's Syndrome. I, too, suffered for some 40 years with unexplained bleeding from tooth extraction and day to day cuts. I was only diagnosed as having von Willebrand's this year, and like GRO-A **felt very relieved that at last a condition that I knew I suffered from was actually proved and my complaints about excessive bleeding were not a symptom of my mind.**

Thankfully my son has not inherited this condition, but it appears that other *members of my family* have not been so fortunate. The Green Card that we carry certainly gives us peace of mind and helps us to live nearly normal lives without the fear of bleeding to death. Thank you for giving me the opportunity of knowing that the last 40 years suffering have not been isolated.

Please keep up the good work, as the letters are a source of inspiration.
Name and address supplied.

The Armourpage survey results

A look at how useful the service is

In April 1990 the Haemophilia Society, Armour Pharmaceutical Company Ltd and British Telecom offered a free paging service called "Armourpage" to all parents/guardians of children with haemophilia (under the age of 16). 463 families took up the offer, the majority of which had not previously used such a service and the following is the result of a survey carried out among these families to determine just how useful the service has been and check up on any problems.

The results were overwhelming. More than 50% responded within just two weeks and everyone who replied said that they would recommend other parents in their position to apply for an Armourpage if they do not already have one. No-one had any problems that couldn't be resolved by a quick battery charge or a chat with a Telecom engineer.

Many families felt that having had an Armourpage "life would be impossible without one" regardless of whether they had received a call on the service. The Armourpage offered them increased freedom and peace of mind and enabled the families to lead a "normal" life again, knowing that they were constantly contactable.

In some cases reluctant schools had been more willing to enrol the child and to allow them to go on school trips and join after-school clubs, knowing that if anything happened the parents would be a simple call away.

On a more practical level the use of an Armourpage also reduces the time lag before treatment. This helps ease the pain/discomfort felt much more quickly and the child can be back on his feet within an hour, whereas in the past it could have taken longer than that to contact the parent.

ARMOURPAGE IN BRIEF

Armourpage is a British Telecom Tone Pager which operates in selected regions around the homes of parents/guardians of children with haemophilia. The parents/guardians are given a simple British Telecom Tone Pager and the school a 10-digit telephone number. In the case of an emergency, the school simply dials the number which makes the pager "bleep" within minutes, alerting the parent, who knows to contact the school immediately.

Armourpage has moved from London to BT Mobile's head office in Leeds!

In order to improve customer service a helpline has been set up where people can leave their name and telephone number. We will then return your call to discuss your query.

You can get assistance by phoning the Armourpage Helpline on: 0426 979 388.

Any written enquiries about the service or the pagers should be directed to Katrina Nash or Sue Kozelko at BT Mobile in Leeds.
BT Mobile
Armourpage
Arlington Business Centre
Millshaw Park Lane LS1 0NE

Your existing service will not change.

Armourpage scheme to continue!

The Society are pleased to announce the continuation of the Armourpage scheme during 1992. Armourpage was launched in April 1990 by Armour Pharmaceuticals and British Telecom. This unique radiopaging system is available to all parents/guardians of children (under the age of 16) with haemophilia.

Any parents/guardians who would like further information on the scheme should contact the Society.

PROFILE ON:

Nicholas Lawson Chairman of the Resources Committee and Treasurer of the Society.

Nicholas Lawson has been a member of the Society's Executive Committee for two years, and is Chairman of the Resources Committee and Treasurer of the Society.

"My role on the Resources Committee is basically to act as devil's advocate," he said. "Together with my colleagues, I make sure that there are enough funds available for projects that the Society has in mind, and help to test the viability of those projects before any money has been spent.

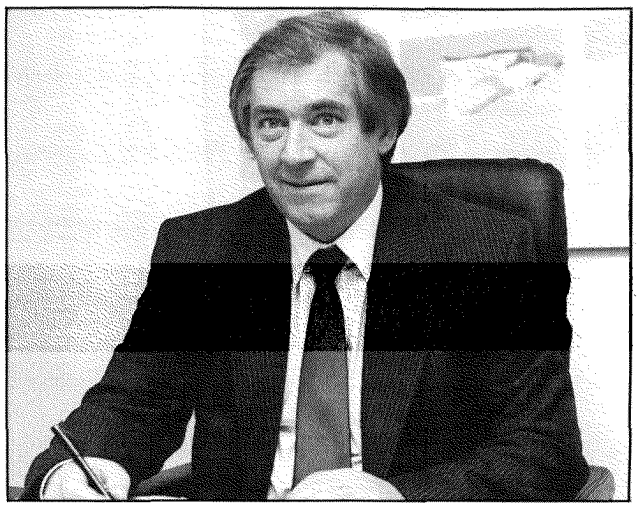
"I became Treasurer last year, a very challenging position, but I am very much aided by the fact that the Executive Committee is such an extremely strong team and together we are able to achieve so much."

Nicholas runs his own company, Lawson International Travel Services Ltd, which has donated the annual Christmas Draw main prize of a trip to the Seychelles for the last six years.

Having built up his firm from a small nucleus to a large concern with an impressive turnover employing 24 people, Nicholas brings a great deal of expertise to his work with the Society.

"With my experience and contacts in the travel business I am able to bring to the Society help with marketing and fundraising as well as financial advice."

Nicholas GRO-C GRO-C is happily married with two sons and lives in Wiltshire.



GRO-C

GRO-C "I am committed to continuing the good work of the Society, especially ensuring that the high standard of service from Haemophilia Centres continues.

"My immediate ambition is to see the terms "Chair" and "Chairperson" removed from the terminology of the Society!" said Nicholas.

NOT RELEVANT

NOT RELEVANT

In reply

Sir:
I have read with interest the views of Drs. Hampton and Makris published in the last edition of The Bulletin.

Dr. Makris infers the monoclonal antibody purified Factor VIII only comes from paid donors. This is not so. Monoclonal purified Factor VIII available in the UK comes from both paid and unpaid donors.

He also infers that there is more hepatitis C amongst the paid donor population. Again, this is also not so; the published figures for the UK show a range of 0.3-1.0%. Paid donors used in the manufacture of monoclonal antibody purified products show a similar range. This puts to rest the myth that paid donors are more likely to harbour infection.

While there is no dispute that the current NHS 8Y is an effective treatment in the management of haemophilia and now has a high degree of viral safety, Drs. Hampton and Makris's conclusions do not withstand close scrutiny. The study referred to by Professor Mannucci, which showed no difference in immune status between patients on a high purity Factor VIII and a conventional intermediate purity product, did not use the monoclonal high purity products under debate.

All studies comparing the use of monoclonal antibody purified Factor VIII with that of intermediate purity have shown a greater stability of CD4 cells in HIV positive individuals to the monoclonal product. A study to be published shortly from another group of researchers will also confirm this finding.

Dr. Makris does not believe that a Meta-analysis (a method of combining the data from different studies to see if there is a trend) on high purity products would show any significance when looking at the effect of high purity Factor VIII on CD4 cell stability. One such Meta-analysis has already been undertaken and published by Serametis (1990). It showed a significantly greater stability with the monoclonal products.

Finally, any clinical studies to show the benefits of high purity products on the immune system are inevitably difficult to perform and may take many years to complete.

However, the main point missed by both Dr. Hampton and Dr. Makris is that to wait for the outcome of all these studies and surveys may be too late. Technology has given the possibility of giving people with haemophilia just the factor that is missing, uncontaminated with large amounts of uncontrolled proteins.

Surely this monoclonal high purity Factor VIII is the logical treatment of choice. In other areas of treatment, the trend is to provide both the treater and treated with the purest product, whether it be made by chemical synthesis or natural extraction. Crude extracts of thyroid, liver, or crude penicillin, for example, are now never given. Why is haemophilia to be treated differently?

R.B. Christie
Clinical & Technical Affairs Director, Armour Pharmaceutical Company Ltd.

Essential reading

Sir:
The Essentials of Haemophilia Care

Thank you for your letter of October 25 and for enclosing the Society's latest publication.

This is a timely publication and I do hope the key messages contained in the booklet help to influence Health Authorities when they enter into contracts for the provision of haemophilia services.

Thank you again for drawing this important publication to my attention.

Ian Donnachie
Chief Executive, St James University Hospital, Leeds.

NOT RELEVANT

NOT RELEVANT

NOT RELEVANT

NOT RELEVANT

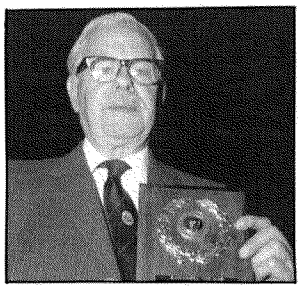
Oliver Memorial Award

Professor Ronald Girdwood, (pictured), Chairman of the Scottish National Blood Transfusion Association, was last year's winner of the prestigious Oliver Memorial Award.

The award is presented annually by the Oliver Memorial Fund in recognition of outstanding work whether scientific or organisational.

The Oliver Memorial Fund was set up in recognition of Percy Oliver who pioneered the Blood Transfusion Service in the 1920's and 1930's.

The inscribed plaque and cheque was presented by Dr. J. Richmond, President



of the Royal College of Physicians. The award ceremony was held at the Royal College of Physicians, Edinburgh on October 31.

US IMMIGRATION

The Haemophilia Society continues to boycott all travel to the USA while the current policy regarding those who are HIV positive remains in place.

The current situation is that those who are HIV positive must obtain a waiver in order that their entry to the USA be legal. We regard this as totally unacceptable.

For as long as this unjustified and unjustifiable legislation remains in place the Society will not enable anyone to travel to the USA by way of sponsorship and staff will not attend meetings in the USA as part of their employment with the Society.

Readers will recall that the Society was the first body to introduce a boycott in September 1989 in connection with the XIX Congress of the World Federation of Hemophilia. This was followed by similar actions by many other organisations including the Red Cross and Red Crescent Societies, the European Community, the World Health Organisation, as well as many other non-government bodies. Few, if any, of those organisations have 'stuck to their guns' and we feel this is the moment to restate our own position clearly.

What's in a name

In today's "let's give it a label" society a great deal rests within a name and it's for that very reason that the Society is at the forefront of ensuring people with haemophilia are able to maintain their individual identity.

The tag "haemophiliac" has been perpetuated both among the press, general public and even among health professionals but it is not a term which the Society feels adequately reflects the true situation.

"Quite simply people with haemophilia are just that, people with a certain condition," explains David Watters, General Secretary. "When the other term is used it merely describes a condition and puts the person into an abstract.

"We are about caring and compassion not about putting people in pigeon holes, so let's be clear it's people with haemophilia clear and simple."

NOT RELEVANT

BPL
BIO·PRODUCTS LABORATORY

The Bulletin has a new sponsor for the year. The Society would like to extend its grateful thanks to Bio Products Laboratory who have kindly donated a sum to pay for the publication of The Bulletin throughout 1992.