Construction Slightly Behind Schedule But

Elstree Still Within Budget

Construction of the new factory at Blood Products Laboratory at Dagger Lane, Elstree has fallen slightly behind schedule, but the project is still within the original £35,000,000 budget.

'It's not the building that is causing the problems', explains Product Services Manager Norman Pettet. 'It is more a case of equipment not becoming available on schedule."

Some of the blood is used as

whole blood in hospitals, while

a large part is used to prepare

blood components, separated

into a part containing the red

blood cells and the fluid part of

plasma. This activity takes place

the fresh plasma is frozen in

special plastic bags and then

delivered to BPL at Elstree who

then process it to obtain several

different products. These pro-

ducts are used throughout the

At most Transfusion Centres

at the Transfusion Centre

'It only takes one supplier to fall behind on a delivery date and the entire programme is affected as machinery has to be installed in a specific order, and the slightest delay on delivery of just one item can throw our plans off course and installation of other equipment gets held

Members of the Society's executive committee visited the Laboratories in February to review progress. The Laboratory first opened in 1954, and it has an associated unit at Oxford.

Norman Pettet was host for the visit, and Dr. James Smith came over from the Plasma Fractonation Laboratory at Oxford to talk to the Group.

THE AIM

'The aim of the Elstree laboratory is to prepare from human blood certain fractions which are used for the prevention and treatment of disease' according to Mr. Pettet. 'It also carries out tests which help diagnose disease in patients, and research and development on components of blood and on methods of purification, and when appropriate new products are investigated and developed.

Blood, given voluntarily and without charge by donors of the National Blood Transfusion Service, is taken to 14 regional centres in England and Wales.



It was a cold and chilly day when the Society party toured Elstree. In the centre of the photograph is George Kirman, and from left to right, the others are: Peggy Britten, Rev. Alan Tanner (Chairman), John Prothero, Keith Colthorpe, Norman Pettet (Product Services Manager, Elstree), Clive Knight and

Health Service, the Public Health Laboratory Service, and the armed forces.

A second source of plasma is the small proportion of blood donations which have not been used before they fall out of date in hospital blood banks or Transfusion Centres.

This time-expired plasma is pooled into plastic bags which hold five litres. The plasma is then frozen and sent to Elstree.

Plasma is a rich source of proteins, some of which are separated at the BPL and prepared for medical use. Fresh plasma contains protein frac-

tions necessary for the correct clotting of blood, and both Factor VIII and Factor IX are prepared at Elstree in a form easily absorbed by patients either in their homes or at hospital.

30% OF THE NEEDS

In 1985 the laboratory supplied about 30% of the needs for heat-treated Factor VIII in England and Wales, while the remainder was imported at considerable cost to the NHS.



Some parts of the new building were looking very smart and functional . . .

By 1988 we expect to see Laboratory putting out all the heat-treated requirements for England and Wales', says Norman Pettet.

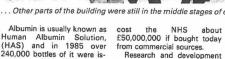
Fresh plasma and time-expired plasma are also important sources of other protein fractions, for example immunoglobulin and albumin.

Immunoglobulins are antibodies the body needs for defence against infections and other diseases. Immunoglobulins are prepared at Elstree for wide use by the medical services in the prevention of measles, mumps and hepatitis, as examples.

Some antibodies are not often present in routine blood donations and these have to be collected from specially selected donors at Blood Transfusion Centres by a process known as plasmapheresis. In this instance plasma is collected from the donor and the red cells returned to the donor at the time of donation. In this way plasma with antibodies against tetanus, chickenpox, rabies and the rhesus factor, which is used in the prevention of rhesus disease in babies, is sent to Elstree for further processing.

ALBUMIN SOLUTIONS

Albumin solutions are used to maintain fluid levels in the blood of patients with severe burns, after bad accidents, and during major surgery.



amount of albumin derived the understanding of the profrom nearly one million blood duction processes and in the donations. development of new and safer Between 1975 and 1985 blood products. production of Human Albumin Solution has exceeded 1½ mil-

The main emphasis is in improving Factor VIII and Factor IX concentrates to reduce some

also plays an important role in

risks to patients where those risks still exist in these products.

In 1976 BPL received 47,000 litres of fresh plasma. Today the figure is 260,000 litres per annum. During the intervening period the amount of time-expired plasma has remained at about 50,000 litres p.a., reflecting the best use which has been maintained of

the whole blood collected. Between 1976 and now the annual output of blood products has risen to the maximum which can be produced at the present premises at Elstree. For example, Factor VIII issues each year have risen from 6.5 million units to 30 million units. HAS production has more than doubled from 100,000 to 240,000 containers p.a.



sued for use in the NHS and this

lion bottles, which would have

Clive Knight and George Kirman take a look into one of the special vats, installed high in the top of

NEW PREMISES

'So you can see why we need new premises,' comments Norman Pettet. 'Things are well under way and the new factory should be commissioned in late

'It will require an annual input of 450,000 litres of fresh plasma, which is three times today's production capacity at Elstree, just to meet the required output for Factor VIII and albumin solutions; besides all other products

IAN LUCAS

Professor Jim Smith Describes an **Exciting Development**

Factor VIII 8Y from lab bench to national product in one year

Sometimes the national plasma fractionators are thought to be slow in responding to the challenge of commercial competition. If you want the best and safest Factor VIII and Factor IX, you might expect to have to wait a little longer.

Last year, Blood Products Laboratory (BPL) pulled out all the stops and leapfrogged the competition with two entirely new heat-treated concentrates of Factor VIII and Factor IX, developed from the lab bench to national products in under a year.

BPL cannot risk experimentation with 1,200 litre batches of plasma, worth over £50,000 as finished products. New fractionation methods especially for coagulation factors, are worked out in its 'pilot plant', the Plasma Fractionation Laboratory (PFL) in Oxford-iust next to the Haemophilia Centre.

In 1983, the Director of BPL and PFL, Dr. Richard Lane, gave PFL the job of making all our products safer from the risk of transmitting virus diseases. He was especially concerned about the high rate of non-A non-B hepatitis (NANBH) in haemophiliacs.

Painstaking work, especially at Oxford Haemophilia Centre and Royal Free Haemophilia Centre, was showing the world just how serious the problem might be

Hepatitis B is less worrying nowadays because there are good tests to screen out infective blood donations and there are vaccines for people like haemophiliacs who are exposed to a lot of blood products, but there are no blood screening tests or vaccines for NANBH.

In fact, no-one is sure what the virus looks like, how to grow it or detect it, or even whether there is more than one virus. Without frequent prospective testing of blood samples, it is quite hard even to be

sure whether a haemophiliac has been infected with NANBH by a concentrate

CLOSING IN

With the help of advances being made at Protein Fractionation Centre, Edinburgh, PFL scientists were closing in on several promising methods for killing viruses by heat treatment when the AIDS 'epidemic' struck haemophiliacs in the United States in 1983.

By the spring of 1984, when most people accepted that AIDS was carried in blood by the virus called LAV or HTLV III, PFL had shown that the national Factor VIII concentrates HL and 8CRV could be heated at 60° or 70° with an acceptable loss of Factor VIII and solubility

But, at this stage, most of the doctors looking after haemophiliacs did not think there was enough evidence that heating NHS products was necessary or that it would kill the AIDS

Meanwhile, PFL scientists began to believe that to be sure of killing all viruses they might have to 'bake' Factor VIII hotter and longer than the current concentrates could stand without becoming insoluble and losing too much Factor VIII

AN IDEA

Lowell Winkelman and Neil Owen had the idea that Factor VIII itself was quite stable to heat, but that its solubility was spoiled by two other proteins. fibrinogen and fibronectin, also present in the crude concentrate. They found a way of removing these other proteins and by September 1984 they had got Factor VIII to a very high concentration and purity.

With the help of Mike Haddon and Helen Evans organising and interpreting hundreds of clotting assays, they showed that the new Factor VIII concentrate (by now labelled 8Y) could indeed be heated in the final vial for at least three days at 80°. That is so hot that you need insulated gloves to handle



Prof. Jim Smith

Just as Dr. Lane took the final decision to develop these laboratory findings towards the next national product, the first confirmation came from Atlanta that the AIDS virus was sensitive to dry heating.

Although it was December before the Haemophilia Centre Directors agreed that they should be aiming at the use of heat-treated Factor VIII concentrate, PFL and BPL had anticipated that decision with a co-ordinated plan.

First, a stopgap effort to provide a heated version of the intermediate purity concentrates-the entire national product had to go through PFL's little 'research' oven. This had been developed by PFL's Vince

Stone with Pickstone Engineer ing at Thetford, and the successful design had to be greatly scaled up to provide BPL with production ovens by April

At the same time, equipment was specified and ordered so that BPL could start making the new concentrate, 8Y. PFL's pilot plant under David Evans helped to push Lowell's 5 litre experiments to the 300 litre batch scale within a month, working out most of the details for BPL's 1200 litre batches. By January 1985, Lowell and David had introduced the new processes to BPL's Coaquiation Factors Production Department

SCALING UP

Then began the real taks of scaling up to 2-3 tonnes of plasma every week, in the face of great difficulties. Peter Prince and John Williams had to marshall their limited resources of staff, equipment and processing areas to take on completely new processes, at a time when planning for the new 450 tonne manufacturing plant was preoccupying everyone's

By February 1985, they had scaled up 8Y to full production batches of 1200 litres and started to accumulate stock towards the autumn release of the new concentrate.

Meanwhile, the advance batches of PFL's pilot production went to clinical trial, to prove that 8Y was safe and effective in haemophiliacs, even after its very severe heat treatment Armed with hard data from Dr. Rizza, Dr. Kernoff and Dr. Jones of the Oxford. Royal Free and Newcastle Haemophilia Centres, we could extend the clinical trial to answer the crucial question-does the heat treatment really prevent transmission of AIDS and hepatitis?

All the laboratory and clinical reports suggest that we have many thousand-fold 'overkill' of the AIDS virus and none of the susceptible first-treatment haemophiliacs in the trial have shown any signs of hepatitis so

But we need the continued enthusiastic co-operation of the Haemophilia Centres and the brave haemonhiliacs who



In the centre of this picture is David Edgar who carried the Haemophilia Society colours in the Glasgow marathon last year. David raised almost £3,000 for the Society.

Mrs.C.Gillespie organised several events in Dumbarton last year and is seen here handing over £691.64 as a result of her efforts, to Scottish Group chairman Andy Cowe.



Pictured at the national Society draw, held at Newcastle, in November, are (left to right): Sharon Hart, Society treasurer John Prothero, Sister Maureen Fearns, Lorna Reynolds (chairman of the Northern Group), George Sanderson and Pauline Sanderson (secretary of the Northern Group).

As though running

in a marathon was

old John Thorne of

Dinas Powis ran to

raise money for the

Haemophilia Society

But he did it! He

minutes, knocking 11

previous best . . . and

raised £467.54p in the

on the basis that

best time!

process.

Society

clocked 3hr 17

minutes off his

John has a

who had just

at University.

haemophiliac son

completed his course

Another runner in

the race was Kevin

Murphy, a friend of

South Wales Group's

Gareth Lewis. Kevin

raised £72 for the

not enough, 54-year-

Among the many attending the national draw were (from left to right); Margaret Walton. Francis Stockdale, Joyce Jefferson, Jenny Wilson, Bryan Collins, Pat Collins, Peter Reynolds and Mr and Mrs Alan





South Wales Group's 'Olde Tyme Music Hall' at the NALGO Club in Cwmbran in October raised £275. It was run by the Everyman Theatre Ensemble.

South Wales Group's Janet Smith is proud of her two boys Darren and Patrick, Unknown to her they raised £26 with a disco at their junior school, held raffles, and staged a Jumble Sale one very wet Saturday when they even made cakes themselves, and raised £40!

Our South Wales Group has been kicking hard to get something done about the poor facilities at their local Haemophilia Centre. They first expressed their concern at their Annual General Meeting last March and have had an uphill struggle to obtain results, but hopefully now improvements are on the way.

It was last December that things really came to a head when the committee made representations to the Secretary of State for Wales and local M.P.s expressing their disquiet at the apparent lack of progress in dealing with the problem of the cramped conditions at the Cardiff Haemophiliac Centre.

The committee were feeling just a little frustrated because it was about eight months since the Cardiff Community Health Council had been notified of the conditions and had expressed their concern to the Health Authority.

The single room comprising the Centre measures only 10' x 20' and has to serve as a visiting room, treatment and casualty room. This means that confidentialitiy is very hard to maintain and there is also no privacy for anyone requiring an examination. Wheelchair patients sometimes have to wait outside in the corridor because of the lack of space.

The Society were also concerned that for the last six months no routine-type blood investigations had been carried out because some patients had been found to be carrying antibodies to the AIDS virus in their blood through having been given infected blood products in the treatment of their condition.

The laboratory conditions did not come up to the DHSS

£2000 FROM WOODBRIDGE



safety recommendations for the handling of such blood

COMMONS MOTION

As a result of their approach to M.P.'s a Commons motion sponsored by Caerphilly M.P., Mr. Ron Davies and supported by 27 other members of the House echoed the Society's concern at the lack of proper care for haemophilia patients and said that they are severely disadvantaged due to the poor clinical and laboratory facilities provided for them.

They recognized that this was in no way the responsibility of the staff whose efforts while Paul Holden, who has a haemophilic son, Craig, has been a great fund-raiser for the Society for many years.

As a result of his latest efforts Keith Colthorpe, a member of the Society's executive committee, travelled down to Woodbridge in Suffolk just before Christmas to receive vet another cheque—this time for £2,000. Well done the Holden family, and 'Thank you'.

working at the centre in trying conditions were greatly appreciated. They also noted that cramped conditions are not conducive to patient well-being, or confidentiality, especially since the extra need for counselling due to the AIDS

They called upon the Government to investigate immediately the situation which had arisen in the Centre with a view to making more facilities and medical care available.

The Commons Motion was followed by publicity in the media. Meetings with the Health Authorities followed and it was learned that temporary accommodation had been identified near the present Centre and that planning is now in progress. Letters had also been received from the Parliamentary Under Secretary at the Welsh Office stating that negotiations were taking place in an effort to promote much needed extra funding for the Centre.

The South Wales Group are now a lot happier than they were and are looking forward to the day when the new work for the Centre is completed.

Many people write to ask how they can raise money for the Society and we thought that it might be useful to devise this A-Z of fundraising. Any further suggestions or ideas would be gratefully received. Please send your ideas to the Co-ordinator at 16 Trinity Street, London SE1.

ANY opportunity, which should not be lost. Aluminium cans which can be sold! Archery

Barbeques, Beetle Drives, Bingo sessions, Bun-fights. Bring and Buy, Bric-a-Brac

Coffee mornings/evenings/afternoons, Car rallies, Cheese and Wine parties, Car boot sales, Cakes, Cosmetics party, cards

- Draws, demonstrations, darts matches, Dances, Dinners, Discos

- Evening Do's, Egg and spoon races

The FUN OF FUNDRAIS-ING-Fetes, film shows; friends to help, flag days, fancy dress

agree to the lengthy follow-up, organised to achieve national to test many more batches rolling off the production line.

the other people who need coagulation Factors IX, IJ, X, XI, VII. XIII and fibrinogen-you now have a range of convenient, effective and severely heated concentrates from BPL and PFL, unequalled anywhere in the world.

This time next year we will know whether AIDS and hepatitis transmission have been defeated in the first determined assault. Even if it turns out that we have only punched a large hole in the problem, we will have tricks in reserve to finish the job and guarantee a brighter future for haemophiliacs than looked remotely possible in

- NEVER give up! Neighbours who can help! Nearly new

Open house garden

D

Prizes for lotteries, bingo etc: Parachute Jumps: Society

The QUICK THINKING you'll have to do when raising funds!

- Running things like raffles. Races, Record breaking events

Sponsored-walks, runs, climbs, diets, swims, etc. Second-hand book sales, 'Snowball' lunches, dinners etc. Soft

- The person who ends up doing most of the work!

Tupperware

- Tea parties, tournaments,

'trash and treasure', Tombolas.

- VENUES—so important when attracting VISITORS to your VILLAGE!! Vegetable stall

- Waste paper can be a source of income! Wishing Wells

- Xmas cards and paper

- Could be the question you ask

yourself afterwards!

- Z-z-z-z-z-z the only sound to be heard after a hard day spent fundraising!

NOTE FROM THE EDITOR

With reference to Bulletin Vol 34 No 1 1985, page 1 column 2 paragraph 3, David Watters is quoted as saying 'we need a lot of Factor VIII and Factor IX' and further in paragraph 4 in the same item 'without the imported product the quality of life of those who need Factor VIII and Factor IX would have been much poorer'.

A view has been expressed to the Society that these quotes are misleading in so far as they relate to Factor IX concentrates and may have alarmed Christmas diesease sufferers.

It is true that compared with Factor VIII demand for Factor IX is small - 14,169,000 units compared with 77,056,000 units of Factor VIII.* It is also true that the UK was self-sufficient in Factor IX in terms of volume. However, in late 1984 some doctors took the decision to use imported heat-treated Factor IX concentrates because of the then prevailing doubts about the safety of non-heattreated products. It is a regrettable matter of fact that some 20 UK users of Factor IX had seroconverted by August 1985.4

Blood Products Laboratory at Elstree have been able to supply heat-treated Factor IX (9A) in such quantity to eliminate the need for imports since October 1985. Factor IX has been produced at Elstree in greater part for many years and exclusively since April

As a consequence of the above there was a period from December 1984 to October 1985 when some UK Christmas disease sufferers were dependent on imported Factor IX concentrates. It is to this period that Bulletin Volume 34, No. 1, 1985 refers. * UK Haemophilia Centre Directors' Returns 1984.

WHAT CAN THE SOCIETY DO FOR YOU!

The Society has been in existence for over thirty-five years and its main function is that of representing the interests of people with haemophilia. This is achieved in a number of ways-eg.

Making representations to the

- Securing high standards of

Making publications available to members, doctors, nurses, social workers, physioterapists and other health care professionals

providing help to people with

- Limited support to vital research

More especially the Society car

Keeping you up to date on de-velopments in treatment and care through our literature - this

Answering any questions you have.
Assisting you to obtain Mobil-

ity Allowance for your children. Advising on special travel arrangements, treatment centres abroad and in the UK, Documentation, travel insurance, etc.

Society caravans for UK holi-Arranging exchange travel and

summer camps with special facilities for teenagers with

From Page 1...

At the annual seminar in March this year, AIDS Counselling was a major subject for discussion. It was clear that the most effective help will be in providing for these facilities to be made available locally. Little can be done centrally; counselling is essentially a timeconsuming occupation and one counsellor is able to deal with only a limited number of people.

At the moment, there are only six social workers in the country who are available at their Centres for the care of people with haemophilia and, of these, only two are full-time specialists.

Quite clearly, we must press for this number to be increased and to see that more adequate financial resources are made available for this work.

GRANTS

The Government has made available £310,000 specially for counselling facilities to be provided in the Regions. It is most important that these grants should be used to provide people, rather than equipment, so that more qualified counsellors are available to provide longterm support for all who are in need of this facility. We encourage our members to check the position in their own Regions to make sure that the money is being used for the purpose for which it is intended.

For, if proper counselling facilities are available to provide long-term, as well as immediate support, we shall find the future to be far less threatening than It appeared to be when AIDS first

Already, we can say that the introduction of heat-treated concentrates has made the risk of transmission of the virus by this means negligible, so people who are newly diagnosed as having haemophilia should be free from any contact with AIDS.

THE FUTURE? 'CAUTIOUS OPTIMISM'

Some anxieties remain but, providing these proper counselling facilities are readily available we shall look to the future with cautious optimism as we go forward together.

Even in such a difficult year in BPL's development, it met its promise to issue heated Factor VIII by April 1985, and topped this with the completely new and safer 8Y by September 1985—less than a year from the first news that the AIDS virus could be killed by heat. That kind of performance should give UK haemophiliags a lot of confidence that, when the new fractionation plant is commissioned later this year and the plasma supply from NBTS has grown, production will be well

self-sufficiency in Factor VIII.

- Games, Garden parties, quess

- Helpers!--all those friends

and neighbours you'll have to

- Investments—not necessarily

money, but the attics, full of

Jumble Sales, Jams and

- Knitting for sale! KEY RINGS

with the Society Logo, Knees-

- Letters to local businesses.

- MONEY-the purpose of it

Lotteries, Lucky Dips

the weight

recruit, Hoopla

things!

preserves

And we have not forgotten



Consultant

haematologist

D.I.K.Evans from the

Royal Manchester

Children's Hospital

has written to point

out that he does not

the caption to the

massed group of

out on the fund-

raising race.

issue, we had

adds 'the other

the picture is my

colleague

picture showing the

cyclists about to set

reproduced in our last

D.I.K.Evans down as

coming from Alder Hay.

'Furthermore', he

individual shown in

Dr.R.F.Stevens, who

actually took part in

I only started it off'.

the bike ride, whereas

Apologies all round.

work at Alder Hay. In

SKYDIVE **COLLABORATORS** STAYED 'MUM'

There are not many 'mums' who would jump out of aeroplanes (with a parachute, of course). But Margaret Wheeler did, raising £1,000 for the Society at the same time.

Margaret lives in Surrey, and has a haemophiliac son, Philip (5). Her twin sister Janet, a member of our South Wales Group, has a haemophiliac son Colin (3).

If Margaret had done as her mother told her, the Society would only have got £600, but as it turned out we benefitted by £1,600!

In this picture a proud Philip Wheeler (5) waves the cheque handed over to the Society's treasurer John Prothero by his 'mum', Margaret. Gathered round are family and friends who swam, raffled, jumblesaled, walked their way to £600, and more importantly, didn't let on to Margaret's mum that she was still planning to do her jump.

You see, like all good daughers Margaret told her mum that she was going to do a sponsored parachute jump. But mum, Rita Eyre, said 'No'.

Now you may have noticed that daughters do tend to have wills of their own-and Margaret proved no exception, continuing on with her hair-raising plans without her mother knowina.

Meanwhile . . . Mum was organising the family into fund raising. She appreciated what Margaret was trying to do so got the family involved in jumble sales, raffles, sponsored walks and sponsored slimming. They raised £600.

But as their charity income was rising, Margaret was gently falling ... on the end of silken cords as her parachute glided down on an organised drop at Pangbourne. Margaret got blown off course a little and a fence collided with her as she landed . . . but the Society was richer by £1,000.

Mum's remarks to her daughter when she found out have not been recorded!

NORTHERN HELP

HOLIDAYS WALES

Two special holiday weeks are being organised this year instead of the usual one.

These 'adventure' holidays have proved so popular that there will be a July and an August week.

Holidays offer pony trekking, canoeing, sailing, rock climbing, absailing-and several other active pursuits, all supervised by qualified staff, haematologists and nurses.

The first holiday starts on Saturday July 12, and the second on Saturday August 9.

Get in touch with Carol Holliday as soon as possible if you want to book. Her address is 54 Bastion Gardens, Prestatyn, Clwvd, LL19 7LU

LITERATURE FROM STOCK

Just a reminder to members that copies of our new book "In-troduction to Haemophilia" are available free of charge from Head Office. This publication replaces all the former "Notes for " series, except "Notes for Pa-rents" which remains in print. The

"Introduction Haemophilia" is especially suitable for teachers and careers advis-

Also available from head Office is the Heamofact Special Edi-tion—"Advice on Safer Sex". This publication, which will be of particular interest to members who are HTLV III antibody positive is

available free of charge. Write or telephone for your free copy. Books by Dr. Peter Jones are still available too. They include: "Living With Haemophilia", 2nd edition. £9.49 inc P & P to Society members; "Aids and the Blood", £50 plus 50p P & P.; "Haemophilia Home Therapy", £8 per copy, in-cluding P & P.

The Northern Group has started an experimental telephone information service for haemophiliacs.

It is something like the telephone advice service operated by the Samaritans, and this important group were of great assistance to our Northern colleagues when they set out to set up the new advice service.

Centre in Newcastle if they

need further advice

The service is available one night each week, and enquiries phone in to a specific number where they can talk to people well versed in the problems of haemophilia. Sharing problems is always a good thing and it is hoped that people using the tions such as Hepatitis B. service will then be prepared to refer back to the Haemophilia

haemophilia seem to have an in-built survival-factor which

So, of all people likely to be affected by AIDS, they have the strongest inner resources for coping with the problems created by this new feature in their lives.

However, we still have the that all concerned are providing adequate support for them as more attention must be given to

For instance, we have heard some distressing accounts of the insensitive way in which people have been told the result of their HTLVIII tests. It should now be firmly established practice for this information to be given only after proper preparation and with the opportunity for individual counselling to follow, when the information has been THE HAEMOPHILIA SOCIETY

P.O. Box 9 16 Trinity Street London SE11DE Telephone: 01-407 1010



AIDS OR PSEUDO-AIDS?

"The only thing we have to fear is fear itself"

These words of Franklin D. Roosevelt may be appropriate as a thought-for-the-day for people with haemophilia as they consider their own position with regard to AIDS. A year or so ago, a heavy atmosphere of gloom descended whenever AIDS was discussed by them or their familles but now we are able to study the subject with greater understanding and with more information about the risks involved. We have come to see that in some other groups one of the most dangerous features now is in the development of Pseudo-AIDS, anxiety about the condition which often arises through unfounded fears based on inaccurate information.

People with haemophilia have the advantage over these other groups in the community in coming to terms with the realities of the present situation.

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

Member of the World Federation of Hemophilia

Assistance Act 1948 and the Charities Act 1960 (230034)

Registered in accordance with the National

To begin with, they are familiar with the atmosphere of hospitals, and are used to doctors and nurses examining them and administering treatment. They are acquainted with the language of medicine and generally are philosophical in receiving bad

EARLY DAYS

From their early days, they have had to accept interruptions in their schooling, their work and their social occasions, due to bleeding episodes.

In recent years, while enjoying the advantages of the improved life style brought about by the introduction of concentrates. they have also developed their own way of coping with difficulties from unexpected complica-

All in all, people with

enables them to accept and rise above new hazards as they occur.

major responsibility for ensuring they negotiate this hurdle and we have come to see that much counselling people with haemophilia, their families and their

assimilated.

At the same time, opportunities must be found for members of the family and sexual partners to be given accurate information



about the nature of AIDS and the way in which it may be transmitted

We know, and must help others to understand, that there is no risk in the normal day-today contacts which we have with each other and that there are now well-defined guidelines to be followed in sexual activity.

COUNSELLING

However, the transmission of information is not in itself sufficient, for people vary in the way in which they accept it. The counselling facility is of vital importance in allowing each person to express his own reaction and articulate his own anxieties, so that he may see how far his own life-style should be adjusted.

Cont. on Page 2

Honorary chairman of Northampton & District Group Bob Emery is seen here accepting a cheque for £450 from Duston Carnival Queen. The money was the proceeds of Duston Carnival held on one of those rare sunny days last year-September 7. Duston is a small village near Northampton and the carnival was run in conjunction with a fete held at the local community centre, where Bob Emery ran a stall for the

Editorial Board Rev. A. Tanner MA C. Knight BA (Editor) C. Milne BSc (Assistant Editor

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