Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392199

The Bulletin

1990 – No. 2

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

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CONTINUING IMPROVEMENTS IN PRODUCTION AT BPL ELSTREE

by Ernie Gascoigne

It is almost three years since H.R.H. the Duchess of Gloucester opened the new £60 million production facility at the Blood Products Laboratory (BPL) in Elstree. And during that time scientists and production staff have worked to maximise production of factor VIII – with some very impressive results.

After some initial teething problems, the new production facility is now fully operational. For example, BPL have processed nearly 500 tonnes of plasma in the past year – a far cry from the 180 tonnes processed back in 1987. That obviously increased the amount of factor VIII BPL can produce – as do improvements in manufacturing efficiency. BPL scientists and production staff have together successfully increased the yield of factor VIII by over 40% in the past twelve months. This means that in the future more NHS product will be available for the treatment of people with haemophilia.

NEW BUILDING

Continued investment at BPL means that a new Quality Standards building will be opening in a few weeks. This building will ensure that the BPL staff responsible for maintaining quality assurance will be working in laboratories second-to-none. Work has also started on design of a new Research and Development building which will house the scientists who research the production processes.

In 1990, BPL's products, 8Y and 9A, will enter their sixth year in the treatment of NHS haemophilia patients. By now, over 2,500 people with haemophilia have received factors 8Y and 9A; over half these individuals were not infected with HIV at the start of therapy with these products and have remained so after what is now years of treatment. Over 500 of these people with haemophilia who are free of HIV infection have received only BPL factor 8Y or 9A.

Equally welcome is the news that in their fifth year of use, it appears that 8Y and 9A have not transmitted the viruses causing hepatitis, particularly the non-A, non-B type.

Finally, BPL plan a further increase in the output of factors 8Y and 9a during 1990, to help those with haemophilia improve their standard of care.

THE USA, HIV and VISAS

It appears that certain changes have been achieved in the entry regulations for people who are HIV antibody positive. Those changes which involve a relaxation of the requirement to apply for a waiver for a ten day period covering both the International Aids Conference and the WFH Congress. At all other times the restrictions and requirements previously announced will apply.

Of itself this change is to be welcomed and our thanks are due to the staff of both the World Federation of Hemophilia and the National Hemophilia Foundation.

The UK Executive Committee will consider this matter and report any change in our current boycott of all travel to the USA using Society resources in due course.

CAMBRIDGE CARTWHEELERS

GRO-A

Now here's an idea for all Groups to get their committee's active and in good trim. Cartwheeling. It's quite easy, doesn't involve any capital outlay, and anything the young can do the 'oldies' can do better (!) so we keep hearing.

GRO-A (10) and GRO-A GRO-A (8), have set the precedent, raising £732.40 by cartwheeling round five local pubs in GRO-A their Suffolk home-town.

GRO-A 's brother GRO-A who had haemophilia, was only 10 when he died less than two years ago, and she has been keen on fundraising to help other sufferers ever since. It was her idea to go cartwheeling and on November 25, backed by mothers and teams of people with sponsorship forms and collecting boxes the girls undertook their intrepid stunt.

The £732 proceeds were divided equally between the Haemophilia Society and the Cambridge Haemophilia Centre.

GRO-A 's previous major fundraising effort was a sponsored 'silence'. She kept quiet for two hours and ended up with £225 to shout about. H'mm. Another good idea for committees?

CONTENTS

You don't just sit in a circle

GRO-A *a Society member, looks at Haemophilia Support Groups*

It is difficult to summarise in one sentence what a support group is because of its very nature. It comprises people who can give or share their feelings and yet receive the encouragement from other group members.

Support groups can be places where one can confide and share the privacy and humour but at the same time take the responsibility of preserving the confidence of the others. It enables others then to give more freely yet at the same time, keep the trust of the group. It allows the sense of security to be kept and preserved for the next time or when they need it.

It may comprise people with similar natures who can relate their own situations with others, but without criticism or judgement. All too often, we go around judging others and even ourselves, using the words like "I should have done that . . ." These words just add to our burdens. Other times we criticise others, yet it is the old case where we point one finger at one person or group, we are pointing three others at ourselves. We need to be a little kinder to ourselves.

A support group is made of people with varying and different outlooks and ways of dealing with life. It therefore changes as the people change within the group and many of the shared ideas will vary from week to week, arising from one's own experiences.

One person in the support group wrote these words:—

To some people, a support group might mean that you all sit in a circle and go around talking about your problems, which in some cases is true; but in some groups its better to call it a support and social group as half the time you can be talking about other different things away from haemophilia.

It's usually easy-going and not strict and proper and you can come along and not even talk for the whole time you are there. There is only one rule that's best kept to and that is confidentiality where it is needed. The good thing about the groups is hopefully that you can go and talk about the problems and come out feeling better for it.

If some people are nervous about talking about their problems, it is sometimes more helpful not to push but to let them express themselves in other ways, even if it means not talking. These support groups are not "encounter groups" and psychology or psychotherapy is not thrust on anyone. I for one, do not like it done to me.

I FELT ANGRY

The support group was thought of when in bed with a bleed in my ankle and I felt angry. Angry at the fact that there were a few people who could and did exploit those who were vulnerable, such as people with some form of disability. I expressed my feelings to a social worker and he suggested that I start a self-help/support group. After that, I contacted the main Haemophilia Centre social workers and counsellors in London. They were encouraging and in some cases very enthusiastic about the idea. One director suggested that we had a group in the east of London, to cater for people who have to come from a long way off. If we do have few people from a particular area, I would be only too happy to help start it off the ground.

There has been some vague criticism about the support group, in that it is used as a platform to voice one's own particular lifestyle or medical treatment. Clearly, a support group is there to listen and support, but not to thrust one's own belief onto others. For instance, if there is some uncertainty about medical treatment, a Haemophilia Centre doctor or counsellor are better qualified to deal with these queries. If someone is having difficulties with benefit, there is somebody at the Haemophilia Society who specialises in that aspect. It is rather like the recent "AA" ads on the television, "No, but I know someone who does."

If on the other hand, we as people can learn to help ourselves, we can stop feeling like victims and stand up as human beings. We share and learn from our varied experiences and realise that others shared similar difficulties. How did others manage to get over them? By talking about them, we can realise that for some unexplained reason, they were not as big as we imagined. They can be overcome.

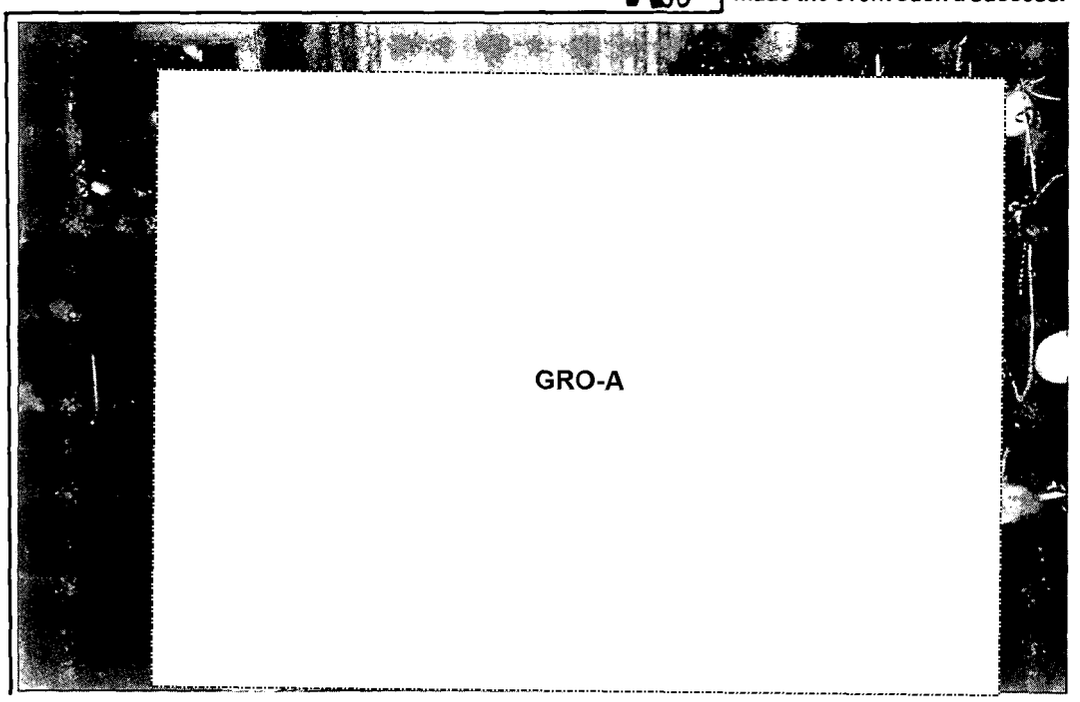
One important factor I learnt from attending a group at the Royal Free Hospital in the early eighties, was that we were individuals and not a blob of people with haemophilia. We have fathers and mothers, we have relationships and we relate to others and they all relate to us. How do we live with our families and how do they see us? Do they see us as people with haemophilia or in my case, a nauseating brother who has a bad temper when he has a bleed. By sharing those experiences with others, we can realise that there are a whole host of other factors that make us who we are and not just people with haemophilia.

JONATHAN COOPER IS LEAVING

It is with very real sadness that we let our readers know that Jonathan will be leaving us later this year to take up a place in Law School. By the time he leaves he will have been with us for three years and in that short space of time he has achieved a great deal for the Society and people with haemophilia. A fuller appreciation of Jonathan's service to the Society will appear later. In the meantime we are grateful to him for his contribution to our work and sad that he will be leaving.

HAPPY CHRISTMAS ON MERSEYSIDE

Merseyside Group staged their Christmas party for children at the Griffin Hotel on January 14. They've sent us a colour picture of everybody enjoying themselves, and although it may be difficult to pick him out, Santa was in the heart of things distributing 'goodies'. A special puppet show was laid on, and Group Secretary GRO-A who sent us the photograph wishes to thank eveybody who made the event such a success.



An Open Letter to Haemophilia Centre Staff

from Shirley Mallon, Chair of the Social Workers' Group

If English was not your first language –

- **could you explain your symptoms to your Unit doctor?**
- **could you ask for something for your child?**
- **could you easily find the toilets in the hospital?**
- **would you understand all of the medical information you need?**
- **would your meals in hospital be sensitive to your religious needs or culture?**
- **could you discuss your feelings/emotional needs?**
- **could you read the handouts/instructions?**
- **could you explain your child's health to his school?**
- **would staff assume you live and think in a particular way?**
- **would you feel able to explain the requirements of your religion to the Unit?**
- **would anyone at the Unit notice your needs?**

The majority of staff at Haemophilia Units are white, and of European background – doctors, nurses, social workers, physiotherapists and receptionists. Although they rarely intend to discriminate against patients and carers who are from different backgrounds, they consistently do so.

Most of this discrimination stems from a belief that they treat everybody alike regardless of their ethnic or cultural origins. They offer a service designed for people who are white or European, to people whose life experience may have more in common with Asia, Africa or the Caribbean. In this, they fail to appreciate that different ways of doing things are not inferior to one another. Neither is the British way superior. A service which aims to offer equal treatment has to take account of relevant individual differences.

For those of you who are white, picture yourself on holiday or living in France, Turkey or Portugal. Now go back over each point and work out how well you would get on in that country's Haemophilia Unit.

It is common practice to ask patients to bring their own interpreter to an interview with the doctor. This guarantees that the interpreter can speak your language, but it causes other problems.

UNDERSTANDING IS VARIABLE

As those of you with haemophilia know, the level of knowledge and understanding of haemophilia is variable amongst doctors and nurses who do not routinely work with this condition. They may then have difficulty explaining issues in haemophilia to someone speaking English. Children, relatives and friends rarely have any medical training at all, and yet are often expected to do this, translating medical information they may not understand themselves.

To ensure the quality of information passed to patients, it is therefore essential that the interpreter is selected and specially trained by the Health Service.

Many people confide things to Unit staff which they would not want passed on the families members or the local community. Unit staff often have to discuss issues of an intensely private nature with patients, for instance, safer sex for those with HIV infection. It is my opinion that it is the right of patients to have the facility for such confidential talks with Unit staff. Can this be done with a family based interpreter? Trained interpreters who are attached to the hospital are seen as being trustworthy in terms of following the Health Service Code of Practice on confidentiality.

Ill-health in oneself or a loved one is very stressful. When under stress it is hard to use newly acquired skills, e.g. a foreign language, or to tolerate unfamiliar situations, e.g. hospitals. It is therefore more caring if staff ensure that patients have their needs met in ways which are sensitive to the visitors, rather than the Unit. This may include ensuring that people's names are spelt and pronounced correctly, that staff do not assume they know how individuals from ethnic minority backgrounds live their lives, and that medically trained interpreters are available. Many of these changes could be made without an increase in resources.

BETTER COMMUNICATION

A more sensitive service is likely to enable medical personnel obtain a more accurate description of someone's symptoms and needs, and better communication of an effective way of resolving them. Time spent in hospital, either as an in-patient or outpatient, will therefore be less stressful on patient and carers, and evidence exists that reduction of stress leads to speedier recovery.

All this means that an ethnically sensitive health service would result in better health care for a significant group of the population. So I ask you to examine in what ways is your Haemophilia Unit ethnically friendly and unfriendly and to be active in increasing the former and decreasing the latter, thereby making an active contribution to a more sensitive and efficient service delivery.

CHRISTMAS FUN

A quiet Sunday afternoon in December, the 17th to be exact, and The Royal Manchester Children's Hospital was woken from its slumbers by the arrival of over 150 adults and children bent on fun and frolics – the North West Group's Christmas party which traditionally is the Group's annual winter clan gathering – an excuse – if one was needed – to "muck-in" and get down to some serious partying.

A magnificent spread of eatables was brought along by those attending; the soft drinks were donated by a local drinks firm and the odd drop of harder stuff was seen, from time to time, to be refreshing those parts of the older members that soft drinks seldom reach.

"Uncle GRO-A kept things under control in his now well-practiced M.C. role, organising the children's games and dragging in some very large looking kids from time to time.

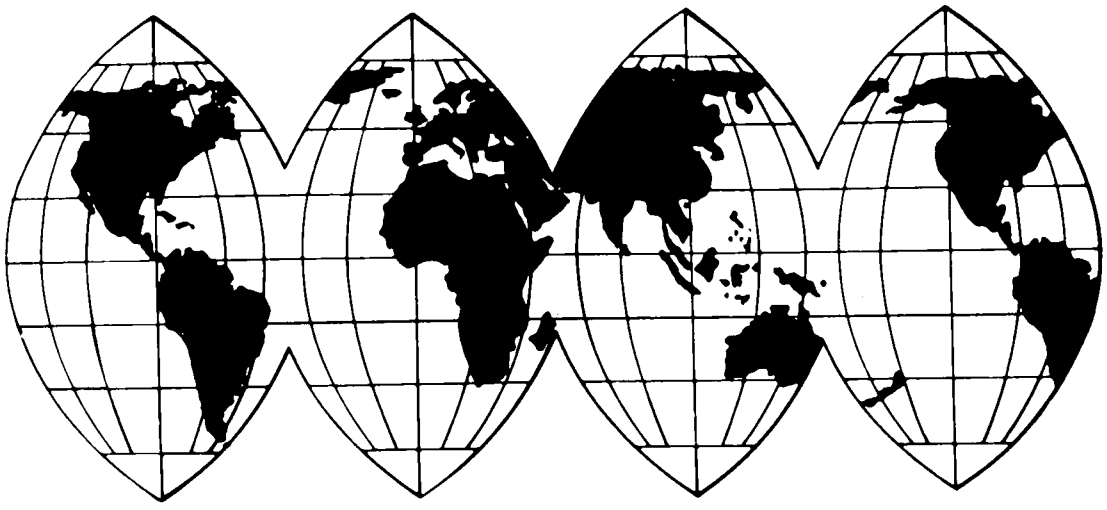
Fancy dress was the order of the day for the children and, of course, a fancy dress competition was held and won by GRO-A GRO-A who came as a clown. GRO-A was a bit restricted by the plaster cast on his leg at the time.

GRO-A "The Joker" GRO-A taking the famous Batman character as the model of his fancy dress, took over the dance floor and gave a solo performance of his Michael Jackson routine. GRO-A GRO-A and GRO-A who were impressive as the Ghostbusters, treated everyone to a demonstration of their busting techniques. Unfortunately any spirits that might have been around earlier were all gone by that time.

Eventually, the children lost their patience and by a combination of threatening behaviour and ear-splitting shouts managed to call up an old fellow in along white beard and bright red coat. The old chap didn't seem to be too put out and even went as far as giving them all a present.

He was accompanied by Garfield who was having an afternoon off from the Palace Theatre, Manchester, where he was appearing with Eartha Kitt in Aladdin. Garfield was subjected to some heavy hand shaking and serious in-depth interviews by some of the children.

Once again, the event was a great success and thanks to all those who helped to make it so. Here's to the next one!



AIDS-Related migration and travel policies and restrictions: A global survey

Margaret Duckett and Andrew J Orkin

Travel restrictions have become a significant feature of the response to the AIDS epidemic by a growing number of countries around the world: over 50 countries now restrict the entry of one or more categories of migrants or travellers with HIV infection or AIDS. Migrant workers and students have been refused entry into numerous states, people carrying zidovudine have been refused entry into at least one major western country and deportations of people with HIV infection or AIDS have occurred.

Data regarding AIDS-related migration and travel policies and restrictions have been incomplete and often based on anecdotal reports. The most recent listings prepared by governments report data in respect of 29 or fewer countries with AIDS-related travel restrictions.

We requested 166 governments to provide data on AIDS-related migration and travel policies and restrictions. These data, combined with information from other sources show a significant and growing pattern of restrictions on the mobility of persons with HIV infection or AIDS.

METHOD

A questionnaire was forwarded to representatives and/or governments of 166 states, requesting information on restrictions, if any, on the mobility of persons with HIV infection or AIDS.

Our request for information was designed not to appear to legitimate or validate such restrictions as a necessarily appropriate response to HIV infection or AIDS. Details of exact statutory authority for restrictions, if any, were not sought in this phase of our research. In addition, our inquiry was addressed where possible to consular offices in Canada or at the next nearest mission, in order to obtain a response that was most likely to reflect implemented policy. In many cases, however, our inquiry was forwarded to authorities in the home country. Where no local representative was available, we corresponded directly with health authorities in the home country.

We asked the following questions:

1. Is certification of HIV antibody status required of any of the following applicants for entry to your country: (a) tourists/visitors, (b) students, (c) foreign workers, (d) immigrants and/or (e) refugees?

2. Is retesting of any of the groups of persons in question 1 required at any time after entry?

3. Are there any policies or provisions in effect with respect to foreign nationals/potential entrants suspected of having, or known to have, AIDS?

4. Are there any policies or provisions in effect with respect to returning nationals (citizens of your country) and HIV/AIDS?

5. What provisions are there, if any, for the deportation, expulsion or exclusion of persons with AIDS/HIV infection?

Responses were analysed, and compared and correlated with information from other official and unofficial sources. Where responses from governments were contradicted by reports from other sources, we addressed a further inquiry in this regard to the home government concerned.

ANALYSIS OF DATA

As of September 1989, 102 (61%) of the 166 countries approached have responded to our questionnaire. Data on 122 countries can be reported at this time. No responses to requests for further clarification have been received.

COUNTRIES WITH NO RESTRICTIONS

Seventy-two countries (59%) appear to have no HIV or AIDS-specific testing requirements for any class of entrant (tourist/visitor, student, foreign worker, immigrant, refugee). It should be noted, however, that a medical examination is often a standard requirement of those seeking entry, and many countries with no apparent HIV-antibody testing requirements may not admit entrants with symptomatic HIV disease, acting under general immigration laws. A number of countries specifically referred to such provisions and the possibility of their application with respect to HIV infection and/or AIDS.

COUNTRIES WITH RESTRICTIONS

Fifty countries (41%) restrict one or more classes of entrants. Foreign workers are tested in 36 countries (30%), students in 34 (28%), and tourists/visitors in 16 (13%). Entry has been or will be refused into, and/or deportations are known to have occurred from 32 countries (26%).

Much of the data obtained from sources other than our inquiry was confirmed by the responses from governments themselves. In 13 cases, however (Algeria, Belize, Chile, Colombia, Czechoslovakia, Federal Republic of Germany, Greece, Hungary, Kuwait, Liberia, New Zealand, UK and the USA), governments asserted the absence of restrictions in law or policy, but other information indicates that, in practice, HIV-antibody testing is required and/or exclusion or deportation has occurred. The USA advised that it had no HIV antibody certification requirements in respect of short-term visitors, but exclusions of people found by customs officers to be carrying zidovudine have occurred on a number of occasions.

There is no apparent association between the national rates of reported AIDS cases and the presence, or absence, of restrictions. Restrictions are reported in, or by, both countries with very high, and very low numbers of reported AIDS cases.

(Continued on page 5)

CHILDREN'S CORNER

here is a puzzler for the children. There are 14 group names hidden in this square. Can you find them.

w e s t o f s c o t l a n d r s v o o j
h q m a h g n i t t o n i o w c u w m g
a k o n x a x n l r r f t h h g p i z g
k b n k r i d c g p d e r b y e f x m k
f z u r r e h a m p s h i r e q s f a l
e l z h e m h p j z j y e f c e z c h g
h h p x o t m t i y c m w n l c u f s n
x i z g n s s n u e y q f a j r x p i c
v b z p o g a a x o g y w d m i y e w m
x b r n h l l b e r s h v p g e e i e e
a c i h m j y p a h t c o r n w a l l s
n o y r a m k m k r t y g p r g e d n p
o m v r m f p d o h n r e h t r o n v v
x y d t m i w n i b c o o z b n f h i x
j z b h a k n d r m d b g n q e e j v i
g y w n r q t g v y e v y h d t y m h y
e g p v i y i a h h k v n k t e l l h a
c u a a t q z q d a r m c d h r b n s m
c j e r s e y v k c m n v e y z e g o i
p v q w h a e f f r g s q f s i f p u n

birmingham
cornwall
derby
grampian
hampshire
jersey
southern
perth
nottingham
northern
northwales
northeastern

lewisham
westofscotland

GRO-A

We are sad to have to inform members of the death of GRO-A champion of the cause of haemophilia in Northamptonshire. GRO-A who was chairman of his local Group, was widely respected for his unstinting work on behalf of people with haemophilia and the contribution he made to Society affairs through his membership of the Council. We extend our deepest sympathy to his wife, GRO-A and her two sons.

EDITOR: Andy Cowe

EDITORIAL BOARD
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Andy Cowe

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Aids Related Migration and Travel Policies

(Continued from page 4)

In many countries, restrictions appear to be based on symbolic, stereotypical or apparently arbitrary reasons. In the cases of Cyprus and Egypt, for example, it appears that cabaret artists or defence contractors, respectively, are the only workers required to be tested for HIV. South Korea and Iraq exempt married people or those over 65 years of age respectively from testing. Many other countries exempt tourists/visitors from testing, and define this class of entrant on the basis of a maximum length of stay ranging from 5 days to 2 years. Finally, restrictions are applied only against applicants for entry from named countries, regions or endemic areas in the case of at least eight countries.

A number of countries reported the existence of HIV or AIDS specific legislation and/or policy restricting migration and/or travel, while others apply existing immigration health requirements to test one or more classes of entrants. At least eleven countries report that they are considering the imposition of AIDS-related migration or travel restrictions.

CONCLUSION

This survey reveals that at least 50 countries now restrict the entry of people with AIDS or infected with HIV. In addition, 11 countries reported that they are considering restrictions. Data has yet to be obtained in respect of 44 countries.

It can be concluded that while a significant number of countries have, or claim to have, rejected travel restrictions as a measure to control the spread of HIV, an increasing number of countries are imposing such restrictions.

The use of restrictive measures as a response to infectious diseases has been discouraged since the mid-19th Century and especially since the establishment of the WHO. The International Health Regulations require WHO member states to refrain from enforcing restrictions for non-regulation diseases; HIV infection and AIDS are not included in the regulations.

Further, in March 1987, a WHO consultation concluded that AIDS-related travel restrictions are ineffective, impractical and wasteful as a public health measure. Jamaica is typical of the countries that report full implementation of the WHO Global Programme on AIDS recommendations in this regard: 'The Ministry of Health has adopted the WHO's principle on International Travel with regard to AIDS/HIV infection and will therefore not be introducing HIV testing for international travel purposes.' (Correspondence with Ministry of Health in Jamaica, June 1989.)

The WHO Assembly has urged member states, and the International AIDS Society has urged all individuals, organisations and governments to protect the human rights of people with HIV infection or AIDS, and in particular to avoid discriminatory action against them in travel and employment. Restrictions that discriminate against people with HIV infection or AIDS, or people from countries with high rates of reported AIDS cases violate a number of provisions of national and international law prohibiting discrimination. A number of countries reported deliberate policies of non-discrimination: 'The keystone of our AIDS Prevention and Control Programme is information, education and counselling, and avoidance of stigmatisation and discrimination.' (Correspondence with the Government of the Republic of Zimbabwe, June 1989).

Each year over a billion people travel or migrate for business, tourism or economic survival. The imposition and enforcement of AIDS-related travel restrictions by a growing number of countries can be expected to have a serious impact on social, economic and cultural exchange.

ACKNOWLEDGEMENTS

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Experiences of Nursery and Primary Schools

by GRO-A

The first of an occasional Series about the education of children with haemophilia

Although I was aware that haemophilia was present in some part of my family I was unaware that it was travelling down my female line. During the first few days of his life GRO-A had nose bleeds. Then when he was 11-weeks-old he was admitted to hospital with what was diagnosed as a bleed in his right ankle joint. My husband GRO-A and I were then told that GRO-A had haemophilia A with a clotting level of less than 1%. After an initial feeling of shell-shock I think we both came to terms with the situation quite quickly. We felt that if he could have a bleed lying in his cot there was little point in mollycoddling him or worrying to excess – if he was going to bleed he was going to bleed.

I had no particular fears for GRO-A when he started nursery school at the age of two. The nursery school was at the top of the street where we live and they knew that they could reach me quickly if this was necessary. I think it is important with any medical problem to be integrated at as early an age as possible and this is the main reason why I wanted GRO-A to start nursery straight after his second birthday. He was still having continual problems with his right ankle joint and he was therefore often on prophylaxis. On these occasions I would take him up to the hospital for factor VIII first thing in the morning. Usually I managed to get him back and into nursery within five minutes of it starting in the morning.

KIDS ALL WANTED THE BOOTS

By the time GRO-A started nursery school he was wearing a leather anklet during the day and a splint at night on his right ankle. By the time he was three he was wearing black Doc Marten boots to support the right ankle. This caused a bit of a problem for some of the mums who ended up searching the whole of Edinburgh for "boots just like GRO-A's" for their sons! The children in the nursery all accepted without question that there were times when GRO-A could not walk. On these occasions they would simply get onto his level and continue the game they were playing. I've sometimes had a little group of children in the house all going about on their knees.

His nursery education worked very well. He was never excluded – things would be done in a slightly different way if he couldn't fully take part, or made to feel different – any more than the difference between someone having brown hair and someone having red hair. We have brought GRO-A up never to be separated or excluded because of his haemophilia. If he has a friend round to play and he needs to go to the hospital the friend goes along with him, or if he needs factor VIII when his friend is with him the friend is not sent out of the room. There is no embarrassment on either side about treatment being given. On his sixth birthday GRO-A had a bleed in his right ankle and we actually ended up giving GRO-A his factor VIII as his friends were arriving for his party. It was nice to see the children pouring in shouting "Hi GRO-A" and chucking presents at him as if nothing was happening.

GRO-A was enthusiastic about starting at the local primary school. When I enrolled GRO-A I gave very full information about his condition and afterwards sent a letter enclosing literature on haemophilia and saying that I would be delighted to come along to the school at any time to have a chat to GRO-A's teacher. I was therefore disappointed to get no reply to this letter and in fact no further communication from the school at all. At some later stage I learned during a conversation with the recently appointed Haemophilia Sister that she was going along to the school to talk to them. Neither GRO-A nor I were asked to attend and we had no idea at the end of the day what the school staff knew or did not know about GRO-A and haemophilia.

The one thing I had suggested to the Haemophilia Sister was that as the P1 intake was staggered over a three week period, it would appear sensible to start GRO-A on day 1. Having an outline knowledge of what haemophilia is, without an intimate knowledge of how it affects the person you are dealing with is not good enough.

STARTED SCHOOL

When GRO-A actually started school he was on long term prophylaxis to control bleeding in his right ankle joint. As he was still on hospital treatment I used to leave the house on Monday, Wednesday and Friday morning at 8.00am to take him up to the hospital for factor VIII and then dash back to get him into school for 9.00am. On Tuesday and Thursday lunchtimes I used to pick him up from school to take him to hospital for physiotherapy and then take him back to school for the afternoon. During the summer holidays after GRO-A's first year at school my husband GRO-A took over the administering of the factor VIII. This made a tremendous difference to our lives as did the provision of a wheelchair for GRO-A when he started his second year at school. This enabled GRO-A to get straight into school after a bleed and generally gave him more mobility and independence when he was off his feet.

The negative attitude of the school was very disappointing and shortsighted. Lots of minor things could have been ironed out at the very beginning if our offers to come along and have a chat about GRO-A and haemophilia had not been ignored. GRO-A had a lot of unneccessary bleeds to his right ankle during his first two years at school e.g. being tramped on going up or down stairs because he was in the middle of the group, being kicked when the class were sitting on the floor round the teacher or being trampled on when he was standing in line to go into school. This is irritating when GRO-A has been on prophylaxis for a long time and you are trying to control the bleeding and there is a constant string of bleeds caused through thoughtlessness. GRO-A had more bleeds caused through incidents like these than he had playing in quite a rough primary playground. We did not discover until GRO-A was in Primary 2 that the school janitor had not been told about his haemophilia and consequently would not let him into school at lunchtime if he had a bleed.

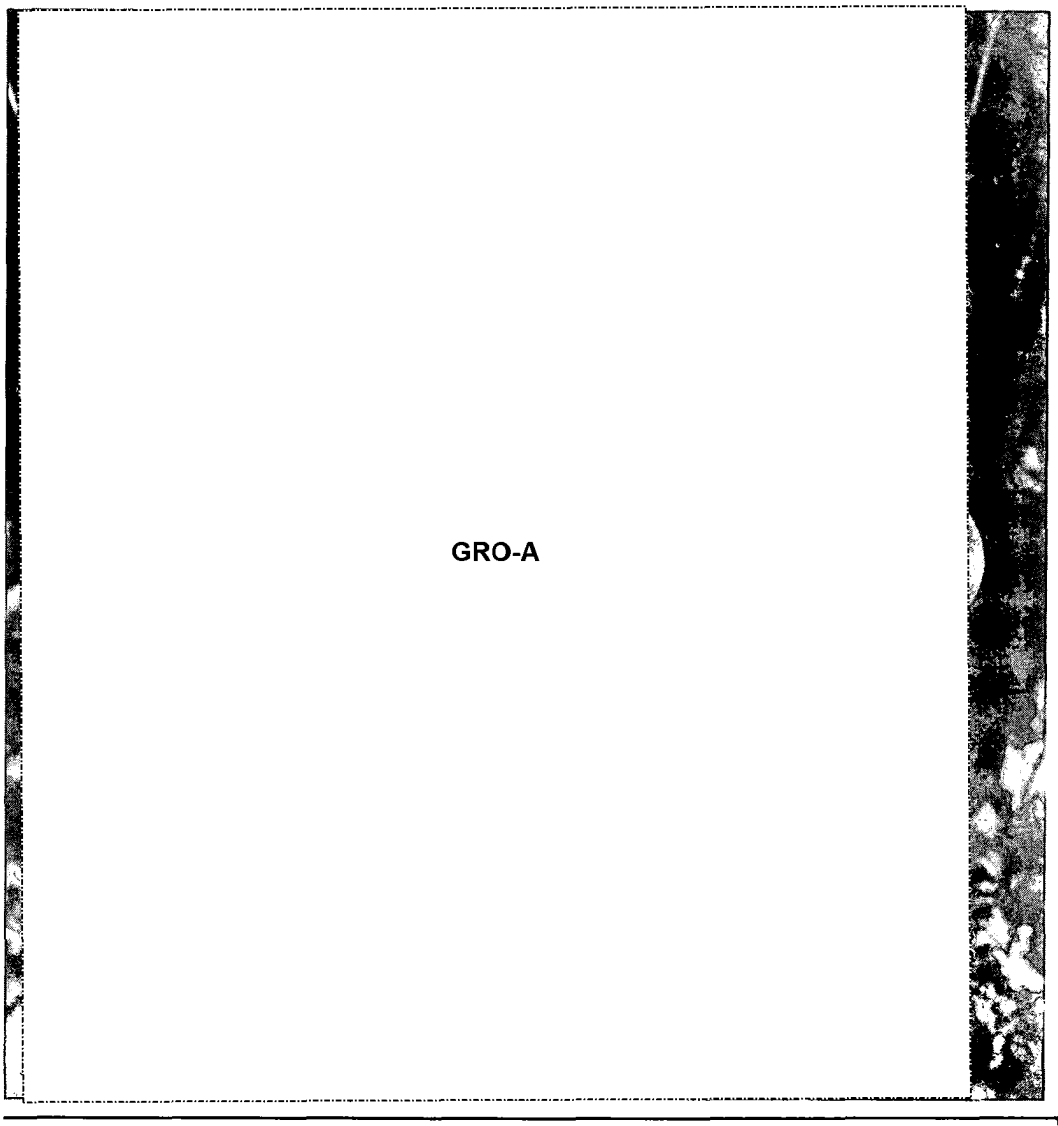
Although we felt that it was important that GRO-A should miss as little school as possible and therefore home treatment and the wheelchair were a great boon, the reaction from the school was different. They seemed to prefer GRO-A to be removed from school if he had a sore ankle even if he had had factor VIII in the morning and we would not be giving him any more.

About two weeks before the end of GRO-A's second year we received a letter from his headmaster suggesting that the time had come to review GRO-A's continued attendance at his school. To put it mildly we were surprised as there had been no indication that there was any problem with GRO-A being at the school. An initial meeting with the headmaster revealed that the problem was largely that the school was not staffed to give GRO-A assistance on the stairs or help him to the toilet when he had a bleed. This seemed totally out of proportion with the problem. I had a chat with GRO-A's doctor and the Haemophilia Centre nurse about this and she agreed that it would not be a good idea to change GRO-A's school.

She offered to come to the school with us for a chat. In the end a very large meeting was arranged with doctors from Community Health, representatives from the Haemophilia Centre, teaching staff and ourselves. The meeting, although belated, proved to be quite productive. The school felt if GRO-A stayed at the school they would need a special auxiliary for him. Our reservations about this were that it could make GRO-A less independent and make him become more of an invalid if it was not handled correctly and these views were shared by the doctor from Community Health.

An auxiliary was appointed ready for the start of primary 3 and was introduced as an auxiliary for the whole class. We were also invited to the school to meet the auxiliary and have a chat with her about GRO-A. Treated in this way it is working out fine. I have now developed a system of weekly sheets which goes in GRO-A's school bag every day. From this the teacher can see if he has had a bleed the night before and where, if he has had

(Continued on page 7)



At the touch of a button

A new free paging service linking schools and parents at the touch of buttons enabling children with haemophilia to get treatment much quicker and offering parents a little more freedom has been launched in a joint venture between Armour Pharmaceuticals and British Telecom.

They've called the small gadget Armourpage. Parents of children with haemophilia hold a simple BT tone pager while the school has a 10-digit telephone number which they simply dial to set off the 'bleep' on the pager.

As long as the parents are within the specified region they will be contacted within minutes of any crisis.

The Society has co-operated in the trials through the GRO-A family in Liverpool, the [illegible] from GRO-A and GRO-A in GRO-A and a quote from Mrs. GRO-A probably sums up the value of this new idea: "Armourpage has improved the quality of our lives no end, who would think a little black box could do so much."

Society Chairman, the Revd. Alan Tanner, in welcoming Armourpage said that "this new initiative is not only an efficient way of ensuring that children with haemophilia get treated quickly, but also provides the parents or guardians with greater freedom."

TV Presenter Sarah Greene with (left to right) GRO-A (8), GRO-A (5) and GRO-A (4½), three of the ARMOURPAGE recipients.

EXPERIENCES OF NURSERY AND PRIMARY SCHOOLS

(Continued from page 6)

factor VIII that day either for prophylaxis or injury, and if he is going to a friend's house after school or being collected by me. There is also a space on the form for the teacher to put comments on. This also provides me with quite a handy record.

Just as the attitude of the school had been disappointing, the attitude of the mothers and the other children was positive and uplifting. GRO-A started school when the AIDS scare was at its height in the press. I was concerned therefore that some parents might be worried by GRO-A's presence. I couldn't have been more wrong. The only time the subject came up was to show concern for GRO-A. A lot of the Mums have been really interested in finding out about haemophilia, and if he is going straight to a friend's house for tea, the mum is not at all put out that he sometimes comes out of school in a wheelchair.

When the school queried whether GRO-A could stay on at the school because of the stairs, I had numerous mothers who came up to me in the playground and offered to come into school and assist GRO-A on the stairs whenever the class needed to go upstairs for TV or library. Quite a few of the mothers have commented that they find it beneficial for their children to have a child with a medical problem in the same class. GRO-A's friends have learnt a lot about haemophilia from GRO-A himself. One little girl was very impressed when GRO-A took a photograph of himself at the controls of a small aircraft during a 30 minute flight – the Edinburgh Flying Club held a charity fly in and took a variety of disabled children up. She later commented to her mother that she wished that she had 'HELPMAFEELIA' then perhaps she would get to go up in an aeroplane!

From my experience with GRO-A's schooling so far, I feel it is important that schools learn to relate better to the parents of children with medical problems. Although medical information should be given to the schools, it is the parents who are living with the child and small problems can be sorted out quite simply because the parents may already have dealt with a similar situation.

Most schools seem to only see the medical problem and do not realise the importance of the child's education. We are lucky to be in the age of factor VIII where the children are not off school long term. Our children can, however, miss a lot of schooling because they have a lot of short absences for treatment etc. but no factilities for help with their education if they should fall behind because the absences are not long enough or predictable enough. GRO-A is now half way through primary 3 and appears to keep abreast of his school work so far, but it does concern me that some of the factor VIII children will drop back in their education although they do not suffer through lack of friends as some of the pre-factor VIII children did with their long-term absences from school.

Jonathan Cooper, reports on a BMA and RCN Conference in Cardiff

AIDS A CHALLENGE TO THE COMMUNITY

At a recent conference organised by the British Medical Association and the Royal College of Nursing on "AIDS a Challenge to the Community", I was very interested by a talk given by Dr James Chin of the World Health Organisation Global Programme on AIDS. During his presentation Dr Chin showed a table included in this article which outlined the risks associated with transmitting HIV during the various known risk activities. The information is based on the known global numbers of HIV infections as of 1990.

Method of Transmission	Efficacy of Passing on HIV	Percentage of total infections at present
Blood transfusion	More than 90%	5%
Mother to Baby	Approx 30%	10%
Sexual:	0.1%-1%	Approx 75%
(Vaginal intercourse)		(60%)
(Anal intercourse)		(15%)
IVDU*	0.1%-1%	10%
Needle Stick Injury	Approx 0.5%	Less than 0.1%

* Intravenous Drug Users Sharing Needles

These statistics point out that the chances of becoming HIV positive from a blood transfusion with infected blood is virtually 100%. They also show that there is a 30% chance of a mother passing on HIV to her baby during pregnancy.

The figures around the risks of sexual intercourse are very thought provoking. The statistics show that the most common method of transmission of HIV is through unprotected penetrative sex. Sixty per cent of all people with HIV have been infected during vaginal intercourse. Dr Chin also pointed out the risks of infection after a single act of vaginal sexual intercourse. There is, he explained, between one in one hundred and one in a thousand chance of developing HIV after having intercourse with a person with the virus. This is the same risk as sharing a needle with someone who is HIV positive. There are also, he stressed, no other identifiable risk activities that can pass on HIV other than the ones listed in the above table.

Also at the Conference was a Dr Vass from Hungary. He ran an informal session on how Hungary is affected by HIV. He told us that their first case of AIDS was diagnosed in 1986. They now know of 206 people with HIV and estimate that there are between 1,000 and 5,000 individuals living there with the virus. He also added that there has been little or no safer sex educational material available to Hungarians. However, they do have a policy, he informed us, of testing all partners of people known to be HIV positive.

I asked him about the number of people with haemophilia who are HIV positive. he told us that of the 517 people with haemophilia in Hungary, 28 people of all ages have been infected. His figures also show that of the sexual partners of people with haemophilia and HIV, 8 are also HIV positive. Dr Vass pointed out that this was nearly all of the partners tested.

Another paper of interest was given by Ruth Simms of the Mildmay Mission.In a paper called "Terminal care for people with AIDS – Is Community best?", she outlined the excellent work of the Mildmay Mission, the first Hospice for people with AIDS in the UK. I have always been impressed by the quality of care and professionalism of that institution.

The Conference was also fortunate to have speaking the Deputy Surgeon General and Chief Nursing Officer of the United States Public health Service. Naturally, she was asked about the U.S. Immigration laws. She told us that for designated conferences, people known to have HIV do not have to apply for a waiver in order to enter the US. Alternatively they are now to be given a 10 day visa with no questions asked. The delegates at the Conference did not consider this to be acceptable.

The final session of the Conference was I felt, the most interesting and relevant. At this point they held what they called a consumer panel – that is they gave a voice to people with HIV infection. This was a welcome break from hearing paper after paper where people talked objectively of people dying with AIDS and their needs. Jonathan Grimshaw of the London Landmark and Nick Banton of Body Positive gave particularly eloquent and stimulating accounts of the needs of people living with HIV and AIDS in the Community. In a question and answer session afterwards, diverse issues were raised such as euthanasia and reproductive choices. I have heard Jonathan Grimshaw talk before. I believe him to be an articulate, wise and rational spokesman for people affected by the virus. At a recent Conference on Civil Liberties he spoke about the human rights of people with HIV and AIDS. He summarised these rights as allowing any individual the right to maximise his or her own potential. There is no justification, he said, for discriminating against a person with HIV. Indeed, the opposite should be the case.

All in all the Cardiff Conference was interesting and worthwhile. However, I do not feel the Conference organisers made the most of opportunities available to them. It could have been a chance to promote a higher standard of care for people with HIV/AIDS in the Community. It did not, I believe, turn out to be such an event. I was also a little dismayed that they had not invited, as speakers, any people from the haemophilia community. There are many people in the haemophilia world with tremendous skill and expertise. This knowledge could have been used at a conference such as this for the benefit for all people affected by HIV.

DIETARY SUGARS

Sir:

I am writing on behalf of the Dietary Sugars Liaison Group. This is hosted by the British Dental Association and also represents the British Paedodontic Society, the Health Education Authority, the Scottish Education Group, the British Association for the Study of Community Dentistry and Action and Information on Sugars. The Group aims to improve dental health in the UK and to promote the prevention of tooth decay by the control of the frequency of intake of sugar-containing foods, medicines and drinks (particularly those containing sucrose, glucose, glucose syrup or dextrose).

Tooth decay can result in severe pain, dental abscesses, infection in the mouth and the need to extract teeth. It can put peoples' general health at risk, particularly those suffering from chronic medical disorders. It is a common cause of absence from school/work and provision of treatment is extremely expensive. Treatment may require the administration of a general anaesthetic and, in some cases, admission to hospital. These problems can create a serious hazard to children and adults already in poor health.

A recent report from the Department of health entitled "Dietary sugars and human disease"[1] stressed that those at greatest risk from tooth decay are children, adolescents and the elderly. Among the recommendations made in the report are:—

- ★ All age groups should decrease their consumption of sugar – containing foods and drinks; these should be replaced by fresh fruit, vegetables and starchy foods.
- ★ For infants and young children sugar should not be added to bottle feeds, sugared drinks should not be given in feeders, and dummies or comforters should not be dipped in anything sugary.
- ★ Those providing foods for families or communities should reduce the frequency with which sugary snacks are consumed.
- ★ Schools should promote healthy eating habits by education and by example by providing nutritionally sound choices of foods.
- ★ Those required to take liquid medicines on a long-term basis should take "sugar free" preparations if these are available.

The Dietary Sugars Liaison Group would like to suggest that you tell your members about this problem and that consideration is given to including it in any future publications.

Please do not hesitate to contact us if you require any further information or assistance.

Yours etc.

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Manchester M15 6FH
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REFERENCE

[1] Committee on Medical Aspects of Food Policy. Dietary Sugars and Human Disease: report by the Panel on Dietary Sugars. London: HMSO, 1989 (Reports on health and social subjects; no 37).

WORKING TOGETHER

by Dr S. H. Davies, ChB, FRCP, FRCPath, formerly a Haemophilia Centre Director, and one of our Vice Presidents

There are few, if any, absolute truths and the laws of science change with new knowledge. Nevertheless science is the only rational way of understanding living structure and function. Some 5,000 years ago early man, and his successors, used their natural senses to recognise patterns of serious disease which they attributed to supernatural causes and which they treated by witchcraft, blood-letting and purging to drive out the evil spirits and to propitiate the wrath of the gods. By the early 18th century AD science had developed sufficiently to significantly influence medical thought and practice and the first medical Faculty in Great Britain was founded in Edinburgh University in 1726. By the end of the 19th century modern anaesthesia had been "born" and Louis Pasteur had shown that minute living organisms could cause infection in man.

The civilian and battle casualties of World War II were a tremendous challenge to medicine. Major surgery, for example, became much safer because of the development of the Blood Transfusion Services (BTS) and its associated technology, of anaesthesia and of the effective treatment of infection by "sulpha" drugs and the newly developed penicillin.

Post war, the diagnosis and management of haemophilia made great strides. In Scotland the BTS, from a rapidly expanding panel of volunteer unpaid donors, provided increasing supplies of fresh plasma and then via the Scottish National Fractionation Centre in Edinburgh potent liquid Factor concentrates, storable in deep-frozen form, and later as freeze-dried powder, storable at 4°C and therefore suitable for self-administration at home.

FREE ACCESS

The National Health Service Act (1948) gave patients free access to the General Practitioner (GP) Services and, through them, to the Hospital Services in which modern Laboratory Services and patient oriented technology, both important in diagnosis and treatment, blossomed. The work of the late Professor R. G. Macfarlane and his associates in Oxford, more latterly from 1959 at the Medical Research Council (MRC) funded Blood Coagulation Research Unit, contributed considerably to knowledge and management of hereditary bleeding disorders including the demonstration of the two clinically indistinguishable, but distinct, factor VIII (Haemophilia A) and factor IX (Haemophilia B or Christmas Disease) deficiencies. Their lead was a great stimulus to major coagulation laboratories which were developed in other Haemophilia Centres which were established from 1952 onwards at many of the major teaching hospitals in the UK for the centralised diagnosis, treatment and management of the 'haemophilias' including national registration of cases.

In the early post-war years people with haemophilia in the Edinburgh area, when in need of treatment and usually for 'joint bleeds', came via their GP and thence Hospital Casualty Department to a "waiting" medical ward in the Royal Infirmary (RIE). This traditional system was too slow to be effective and on admission joint pain and significant swelling was nearly always present. Fresh frozen plasma (FFP) was the best treatment available and because of its poor potency several days of in-patient (IP) care was usually needed in every case. When the haemophilia Centre was established in 1962 in a side room of ward 23 (Professor R. H. Girdwood's ward) in the RIE, arrangements were made whereby a person with haemophilia, on production of his registration card, could summon an ambulance without GP consent and come direct to the Centre; he often arrived before joint pain and swelling were a problem and not infrequently after an immediate infusion of FFP he could be similarly treated as a daily out-patient (OP). Young children who needed admission were sent from the Centre to the Royal Hospital for Sick Children and there managed in collaboration with medical staff from the Centre.

REVIEWED REGULARLY

People with Haemophilia were reviewed regularly as OP's by a specified orthopaedic surgeon and also by one dental surgeon in conjunction with Centre staff. IP treatment, when required, was given in ward 23 as a collaborative exercise. One nominated senior physiotherapist attended most consultations and undertook agreed treatment as necessary. A nominated senior social service worker and an occupational therapist were available when needed.

This centralisation of patient care had many advantages including (1), a considerable rapport was established between patients, their families, relatives and staff; (2), enough patients were available to make rapid comparisons and assessments of diagnostic and treatment methods and to undertake research projects; and (3), all grades of medical and paramedical staff could be properly trained and most medical and nursing students at least saw a haemophilic patient!

In 1954 a Scottish Haemophilia Group was formed and thereafter met half-yearly and alternately in Glasgow and Edinburgh. Like most voluntary organisations it depended on a nidus of enthusiastic, dedicated and public-spirited members for its survival. The meetings attracted a small number of staff from the Centres. It has expanded considerably since then and sub-groups in a few of the other Scottish cities have been formed. The Haemophilia Society of Great Britain, founded in 1952, and to which the Scottish Group is affiliated, has developed enormously since its inception and is now a widely recognised and respected charitable body with a powerful public image and appeal. Its aims (quoting its excellent booklet "Introduction to Haemophilia" and now in its 3rd Edition) are "to provide a service to its members and to all people with haemophilia and related disorders".

It has a Medical Advisory Panel, sends a representative to the Meetings of the Directors of the Haemophilia Centres and has close links with the professional sub-groups of nurses, physiotherapists and social workers specially interested in haemophilia. It works with, and through, local Groups in providing support, information and advice, and where appropriate, financial assistance to people with haemophilia and their families. It provides limited financial assistance for selected research projects. It acts, in a sense, as a form of "Consumer Group", stimulating everybody including Government Departments, members of Parliament and the health care professions!

In summary, Health Care for people with haemophilia is undertaken at (1), intensive care units known as Haemophilia Reference Centres which provide highly specialised and comprehensive care and where fully trained medical, nursing and other paramedical specialists work as an integrated team: they are based at major teaching hospitals; (2), Haemophilia Centres which provide routine care and which refer patients when necessary to the nearest Reference Centre; and (3), Associate Centres which offer a factor concentrate infusion service and act as distribution points for such material to home-users.

THE FUTURE

Finally, what of the future? Hopefully plentiful and safer factors VIII (and IX) concentrates will become available through genetic engineering and biotechnological techniques from non-human sources. This should enable many patients to self-inject and therefore live a fairly normal life. No medication, however, can be guaranteed free from undesirable side effects. Genetic counselling and improved antenatal diagnostic techniques may make it possible to offer abortion of a proven haemophilic foetus at an even earlier stage of pregnancy than at present. It seems likely that many years will elapse before genetic engineering will make it possible, and ethically acceptable, to correct the hereditary defect in a fertilised egg by gene transfer and then transplant it back into the mother's womb. Such procedures unlike present-day organ transplantation, would introduce transmissible genetic material into the recipient and onward into his offspring, thus changing family characteristics. Spontaneous genetic mutation will, however, still provide unpredictable female carriers so that the defective gene will never die out.

The aphorisms "it is not what you do in life but how you do it that matters" and "a round peg best fits a round hole" need to be qualified in that one's career should, if possible, be spent in a job in which one is satisfied and in which one's talents are fully employed. A good school education, followed where indicated, by further academic, technical or other training is generally the best way to achieve this goal. Until recent years, severely affected people with haemophilia were subject to so much recurrent disability that they usually found the goal impracticable. Nowadays with modern treatment many of them can live fairly normal lives but they can still need financial help to achieve this positive approach. Should the Haemophilia Society develop a more objective attitude to education and training and consider helping suitable cases through a bursary, training grant or other award? Some benefactors prefer to invest in education rather than in inanimate projects.

The Cardiff Haemophilia Centre

by Professor A. L. Bloom MB, ChB, MD, MRCP, FRCPath, Centre Director and member of the Medical Advisory Panel

The development of the Cardiff Haemophilia Centre really dates from the invention of cryoprecipitate in 1964. Eleven patients were seen in 1963 at the Cardiff Royal Infirmary where treatment was then undertaken under the direction of the late Professor Harold Scarborough. At that time the life expectancy of a person with severe haemophilia was 23 years.

We moved to the University Hospital of Wales in 1971 and the number of treatments rose to over 1000 in 1979. At first day-patient treatment was undertaken from the haematology or children's wards but with the development of freeze dried concentrates and home treatment this system became inadequate and a room adjacent to the coagulation laboratories was adapted as a treatment room.

A Haemophilia Sister was appointed in 1977 to supervise and co-ordinate treatment. By the end of the 1970's the life expectancy of a person with severe haemophilia had risen to 69 years – almost normal in fact. The one-room clinical facility had always been inadequate and the whole situation altered as the impact of AIDS developed and HIV was identified.

In 1987 the space problem was partly solved by expansion of the clinical facility to a suite of three rooms and a secure laboratory. The clinical suite provides for patients attending for frequent follow up, casual attenders for treatment, counselling etc. It comprises a waiting room, consultation-cum-treatment room and a small office accommodating records. Sisters Jenny Jones and Doreen Davies, a Clinical Assistant, Dr Has Dasani and the rotating Registrar all squeeze in to this office. Especially now that patients are attending very frequently for clinical examination, treatment of infections and with their families, for advice and counselling it is clear that we still do not have adequate facilities.

The Haemophilia Centre is situated within the Department of Haematology and of course patients with disorders other than the haemophilias are also investigated and treated by the Centre staff. Excessive bleeding due to acquired disorders occur in obstetrics or after heart surgery and in many other conditions. More and more patients with thrombotic disorders are seen because the investigative techniques used are similar to those for haemophilia. In fact more people with these other disorders are now seen than are those with haemophilia, especially by the doctors and the laboratory staff.

The Cardiff team.

HOW THE CENTRE FUNCTIONS

New referals are first seen usually in my general haematology clinics. Once haemophilia is established the patients and their families are introduced to the Centre Staff. Affected relatives of known patients are usually seen first of all at the Centre. Patients have open access to the Centre which is staffed during normal working hours. There is a direct telephone line and an ansaphone if advice is needed. After hours patients attend the children's or adult haematology ward and all are seen by the haematology registrar "on-call". Patients who need hospital admission are nursed on the children's ward or on the haematology ward irrespective of their HIV status. If symptoms develop we still look after these new problems seeking the help and advice of appropriate specialists as needed. Sometimes specialised care, for instance, after major orthopaedic surgery, is more expertly provided at another location but we liaise closely and try to recover our patients as soon as possible.

COMPREHENSIVE HAEMOPHILIA CARE

The effective care of haemophilia requires the co-operation and interaction of many specialists.

Although readers may have direct contact mainly with treaters and advisers it is important to remember that the history of treatment of haemophilia in this country is laboratory based. The laboratories and their staff are the foundations upon which the clinical service rests. The main coagulation laboratories are led by the Chief Medical Laboratory Scientific Officer (CMLSO) Mr Steve Lees who is assisted by two senior and four qualified MLSO's. The laboratories offer a comprehensive range of screening and specialised tests to aid the diagnosis of a wide range of bleeding disorders and to monitor their treatment. HIV and hepatitis have had an impact on the work of the laboratory and a special laboratory has been equipped to deal safely with these samples. In this laboratory T4 cell counts and other tests related to HIV infection are performed by Mrs Sue Goodwin, who is unfortunately shortly leaving us to join her dentist husband in North Wales.

The laboratory staff are actively involved in training programmes and as the major coagulation laboratory in Wales we receive samples from all over the country, and even from England for some of the more recently developed tests. Currently we are experienc-

(Continued on page 11)

CARDIFF HAEMOPHILIA CENTRE

(Continued from page 10)

ing a rapid turnover of laboratory staff due to an unattractive pay structure and sadly these reference activities may have to be curtailed.

Genetic Diagnosis The research activities of the Centre will be described below but from these has developed a service for carrier detection and in conjunction with the Institute of Medical Genetics, for pre-natal diagnosis by molecular biological methods (DNA gene probing techniques). Under the direction of Dr Ian Peake, Senior Lecturer in Haematology and Principal Biochemist at the Haemophilia Centre, a group of medical and non-medical scientists has established an active haemophilia genetics laboratory to underpin genetic counselling. It is regretted that lack of financial support from the NHS may mean that in the future this service also will be unable to meet all the demands placed upon it.

THE NURSING STAFF

The nursing staff of the Haemophilia Centre consists of one full time clinical nurse specialist Miss Jenny Jones, and Sister Doreen Davies who works part-time. Responsibilities include the day-to-day running of the Haemophilia Centre and co-ordination of the care of the in-patients, out-patients and day patients. The service is available to both children and adults and of course Sister Sue Bowers on the children's ward and Sister Quarrell on the adult haematology ward and other nurses play a full part in haemophilia care.

Some time is also spent in the community visiting families for assessment and home treatment and also visiting schools to advise teachers and to reassure them. In collaboration with the Social Workers, parents' evenings, and children's parties are arranged which give families opportunity to meet.

Home Therapy At present we have about fifty patients on home therapy. Most are severely affected or require frequent treatment during the year. We like to start this therapy at an early age as soon as a child is co-operative, venepuncture access is good, parents feel able to cope and the home circumstances are satisfactory.

SOCIAL WORK AT THE HAEMOPHILIA CENTRE

The Social Work Department has a long history of interest in, and service to, the Haemophilia Unit. The current staff involved are three senior social workers each with part-time duties – Mary Dykes, Linda Ford and Judith Gibby. One worker is employed by South Glamorgan Social Services Department to spend part of her full-time job on the unit. The other two are employed by South Glamorgan but funded by the Welsh Office and combined, their hours form a one full-time post. The Welsh Office funding started in January 1987 to cope with the increased needs.

Traditionally social workers have had a dual role. One has been to look to those needs specific to haemophilia and the other has been to help meet the needs of patients experiencing difficulties within relationships, or during life crises. A parents' group convened by the Social Work Department brings together young families living with haemophilia and while focussing for the evening on a particular topic, provides an opportunity for sharing experience in an informal way.

Since the advent of HIV and a recognition of its many ramifications, inevitably much time has been spent with patients who are HIV positive, their partners, children and wider families. A patients' self-group has been meeting since March 1987 to foster links between patients and families. It has been especially of value for bereaved members and has established a telephone support network with advisory and financial support from Helpline and other sources. Especially valuable was a weekend away when members could relax and develop coping strategies.

Emotional Support Haemophilia has always been a disorder that involved interaction with emotional states but this has been greatly aggravated by the development of the AIDS crisis. Patients and their families vary in the way that they respond to these emotional challenges and one must also consider the additional direct effect of HIV. Co-operation between doctors, social workers, nurses and psychiatrists is even more important and we now have regular psychiatric sessions allocated to the Haemophilia Centre. Dr Rhoswen Halewood is currently a great source of help with these difficult problems and her work will no doubt continue to increase.

PHYSIOTHERAPY AND ORTHOPAEDIC SERVICES

Although a physiotherapy service has been available for many years until recently it functioned on an *'ad hoc'* rotational basis. In 1988 the appointment of a full time senior physiotherapist, Mrs Fiona Hall, dedicated to the haemophilia service has allowed treatment to become more easily accessible and a more comprehensive and structured service has developed. This has proved to be of inestimable value to patients. Patients are referred to the physiotherapist for assessment of their muscles, joints and physical life-style, and for follow up as needed. If splinting is required this is carried out in conjunction with the Occupational Therapy Department. It is hoped that patients and parents will feel able to approach the physiotherapist as an informed advisor to help them maintain their optimum physical ability through to adulthood.

Periodically a Joint "Joint" Clinic is held between the orthopaedic surgeon, Mr Mike Young and the Haemophilia Centre staff to discuss the orthopaedic management of any patients and to identify those suitable for surgery. These patients are often well-known to the physiotherapist through previous out-patient treatments.

Because of the incidence of HIV infection, patients are admitted with related conditions. These are often respiratory in nature and may involve physiotherapy treatment to help clear secretions from the lungs. Further to this, lung function tests are carried out by the physiotherapist pior to, and following, the use of nebulised drugs such as *'Pentamidine'* and *'Ventolin'*. This treatment can be continued as an out-patient if necessary and as a prophylactic measure.

SERVICES FOR DENTAL SURGERY

The dental hospital and facilities are conveniently located with regard to the Haemophilia Centre. For young patients the Department of Paedodontics has specially trained personnel under Miss Barbara Chadwick who initiate a programme of prevention at an early age and monitor the patients at regular intervals. Many adults patients are treated by an experienced general dental practitioner Mr Chris Lewis, who has held a weekly haemophilia clinic at the dental hospital for many years. Patients are also seen by a consultant dental surgeon, Dr D Adams, or one of his staff. Most patients understand that special precautions are needed and our concern is also that we should not produce any infection in a patient who has lowered resistance.

SECRETARIAL AND COMPUTER SERVICE

One of the main functions of the Haemophilia Centre is the maintenance of treatment and clinical records, for our own use and for the compilation of national statistics. Treatment records are maintained by the Haemophilia Centre nurses and these data and the sites of bleeding etc are entered into the computer with the help of the clerical staff. My personal secretary Mrs Parames Ramanathan, and a clerical assistant, Miss Michelle Thomas, ensure that Haemophilia Centre correspondence and filing are efficiently performed whilst a clinic co-ordinator arranges the formal clinics. We are fortunate a that Dr John Giddings, Lecturer in Haematology and a member of the Centre scientific staff for over twenty years is a computer expert and he has written our programmes and supervises the computers.

RESEARCH

The research group within the Cardiff Haemophilia Centre has been in existence for over 20 years. During the 1970's procedures were developed in order to examine clotting factors in tissues and in blood and special assays were developed which have since proved valuable in routine laboratory use. Detailed studies on the genetic defects causing haemophilia A and B started in 1982 and a series of genetic defects within the factor VIII and IX and von Willebrand factor genes have been detected and studied in detail.

On the clinical side we are taking part in the first trials of the synthetic recombinant factor VIII for the treatment of haemophilia A and recombinant activated factor VII for the treatment of inhibitors. We are also taking part in the Medical Research Council trials of Zidovudine therapy in HIV infected patients and we are working on molecular biological "DNA" and "RNA" methods to detect the virus.

Of course we have other research activities in progress not only in haemophilia but in other aspects of blood coagulation and thrombosis. Currently we are in receipt of grants from the MRC, the Wellcome Foundation; the Welsh Office, the Haemophilia Society, Bayer Pharmaceuticals and other sources as well as our own University of Wales College of Medicine Coagulation Research and Development Fund. Into this has been paid money from donations and that earned from industry from the

FUNDRAISING ON A GRAND SCALE

GRO-A has been a prolific fundraiser for the Society for several years. In this article he writes about the background to his mammoth efforts.

"My son GRO-A was born in GRO-A GRO-A 1981. His haemophilia was diagnosed at Ipswich hospital in May 1983 after he had developed a swelling in his foot. His first treatment was in August that year after he had fallen off his rocking horse and cut his mouth.

His most common bleeds have been in his ankles, with occasional knee and mouth bleeds. His haemophilia is severe and the most serious of his bleeds have meant stays in hospital, including one of five weeks in 1988 for a bleed in his thigh, groin and hip. he was also found to have inhibitors of factor VIII at this time. He had a 10-day spell in hospital last year following an arm injury.

Our first fundraising efforts were made in 1983 when we staged a 'sale'.

In 1984 we formed a committee and by the end of 1989 had donated some £19,000 to the Society. Our main source of income has been dances accompanied by a 'draw', which produce about £600 a time. We get local business and many individuals to donate prizes.

We use two venues for the dances, and one of them is a school where we can run our own bar and thus boost our profits. We hold eight dances a year supported by a superb band of helpers and a regular group of 'customers'.

In arranging the dances and selling tickets we have to thank GRO-A's grandfather, GRO-A, who puts in a terrific amount of effort, while the indispensible team arrange the food are grandmother GRO-A GRO-A GRO-A GRO-A and GRO-A

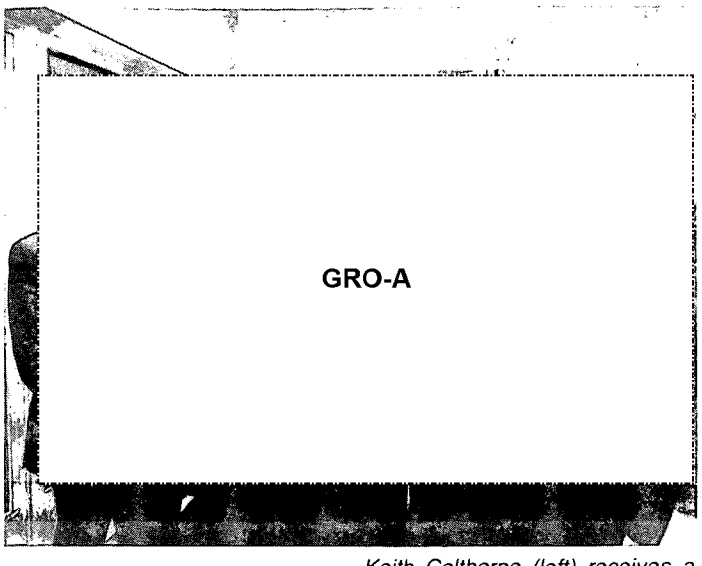
We hold two major sales each year, also accompanied by a draw, and these raise around £500 each time. An on-going source of income is the sale of knitwear made from re-cycled wool, which has now become a 'cottage industry' in its own right.

Another annual fundraiser is the Woodbridge 10km Run where between two and five runners have been sponsored for us. In 1989 I ran with GRO-A and we raised £440.

Local groups often make donations to us, which makes our 'begging letters' worthwhile.

Over the years we have also received donations from individuals who do fundraising themselves, such as sponsored slims (take note D.W.!), angling matches, swims, garden sales, home sales and we even have a lady with a beautiful garden who opens it to the public and passes the entrance fees on to us.

We are fortunate not to have lost any money at any event but some, particularly those dependent upon good weather, can be less profitable than others.



Keith Colthorpe (left) receives a cheque for £5,500 from the Woodbridge fundraisers. Left to right – GRO-A GRO-A GRO-A GRO-A Missing from the line-up were fervent fundraisers GRO-A GRO-A and GRO-A

Executive Committee member Keith Colthorpe comments on the efforts of the Woodbridge fundraisers.

"I have had the privilege to attend many of the dances and functions organised by this small committee and support for their efforts is quite amazing. The dances are normally based on a theme – Country and Western, 60's Night, and there is always a 'live' band. The next dance band is Willie and the Wallies, a popular local group, and they will be giving their services free (the mind boggles at such kindness) to help boost funds.

"I know GRO-A visits local shops and business to get prizes and he leaves nothing to chance with publicity. He telphones people to spread the word and ticket orders come ringing in – with as many as 40 asked for on occasions.

"One of the major contributory factors to their success is that they all get out and about and do things themselves. They don't take NO for an answer!

"They are successful because they believe in what they are doing, and do it well and with enthusiasm. The people of Woodbridge know them well.

"All I can say is 'Thank you' to the people of Woodbridge for their support and generosity. Keep up the good work."

CARDIFF HAEMOPHILIA CENTRE

(Continued from page 11)

sale of reagents, processes and technology. These funds have enabled us to support a research team of six or more scientists and clinicians to complement the permanent staff already mentioned by name who also make valuable contributions to research. These activities keep us all on our toes hopefully at the forefront of knowledge which we trust will not only produce new advances but are also of direct benefit to patients by maintaining our present service at the highest possible level.

CO-ORDINATION

Much of the benefit of individual haemophilia services would be lost if we did not all work together. In the early 1980's Dr Peake and I visited Dr Carol Kasper and her colleagues at the Orthopaedic Hospital at Los Angeles and sat in on a case review. This was most impressive and we have instituted a similar regular multidisciplinary patient review in Cardiff. Every two weeks professionals involved in haemophilia care, haematologists, nurses, physiotherapist, scientists, paediatricians, social workers and others sit round a large table and systematically review the medical, laboratory, dental, genetic and other aspects of a small number of patients to identify problem areas and possible solutions. The aim is that by the end of each year all patients, children and adults, mild or severe on our register will be reviewed.

It is clear that the pattern of haemophilia care has been radically influenced by problems related to HIV but underneath it all remain the other effects of a potentially disabling disorder. I hope that this account will give readers some insight into how we are trying to meet these challenges here in Cardiff.

Acknowledgement: **This account has been compiled from contributions supplied by members of the Haemophilia Centre staff and other colleagues to whom the author is indebted.**

Meet Douglas Jack

This is Douglas Jack, our new part-time fundraiser who works up to four days a fortnight. Douglas, who is based at national office, worked with ASBAH (Association for Spina Bifida and Hydrocephalus) for many years before joining us at the end of last year.

A TROUBLE SHARED . . .

Sheila O'Rourke, Social Worker, St James's University Hospital, Leeds, describes a series of support groups she has set up to help people with haemophilia, their families and carers, and those whose lives are affected by HIV.

Facing problems can be difficult. Facing them alone can be isolating and depressing. Facing them in a group can be painful and frightening, but it can also be therapeutic, an opportunity to share, to give and to receive support and to build bridges of trust. As the old adage says, "a trouble shared is a trouble halved".

When I started work at the Leeds Haemophilia Unit in October 1988, I had little experience or knowledge of haemophilia and it was not without some anxiety and nervousness that I met with my first 'clients'. However, I need not have worried, the patients, their families and carers proved to be excellent teachers and they readily explained the finer points of the care and treatment a person with haemophilia requires.

A warm hand of welcome was extended to me by staff and patients alike and it was not long before I was getting to know the families, listening to their concerns and worries, sharing their joys as well as their fears, and understanding their feelings of loneliness and isolation, whether it was the parents of a newly diagnosed baby with haemophilia, the mother of a boy missing school through severe bleeds, the teenage boy striving for independence but still dependent on others for his care, or the husband with HIV concerned about the future for his family. All these people have special needs, many of them having coped with health and psychological problems for many years, developing a variety of skills and techniques for everyday living, but what many of them shared was a common bond of isolation, a feeling of being alone with their problems, of being caught in a time capsule which only those experiencing a similar situation could fully appreciate.

EVERYONE NEEDS SUPPORT

Virtually everyone needs a social support network of some sort and my inspiration to provide a group support system came from two people well known to our Unit. The first was a young woman called GRO-A whose husband had died from AIDS the previous year. GRO-A was attending the haemophilia children's Christmas Party with her two small children and remarked to me how lonely, how apart she felt from the other families. She no longer felt she fitted in with the haemophilia community, perhaps she was making other parents feel uncomfortable. Her husband had died and there was no-one whom she felt she could 'safely' talk to and GRO-A had a desperate need to talk.

For a variety of reasons we protect ourselves from facing someone recently bereaved – we are embarrassed about what to say, we fear our own emotions perhaps seeing a mirror of our own future. Because death is a taboo subject we put up barriers and are unable to handle the bereaved, leaving them alone and isolated.

A Carers' support group originally met two weekly in the evenings but this presented problems for those without transport and living many miles away from the hospital. It was therefore decided to combine with the patients' support group once a month and use the session as an information sharing forum. Speakers at the group meetings have included a dietician, a nursing sister, a pharmacist and a relaxation therapist. Those attending have reported that it's very helpful to adopt a positive strategy of action and to receive a practical guide to coping with problems raised by HIV. Members have said that it's good to know you can achieve a greater sense of control over your own actions.

A Nurses' Support Group which meets monthly. This group was formulated in the summer of 1989 to help improve the knowledge and skills of the nurses working directly with haemophilia and those affected by HIV. It has been of immense benefit in improving the care and understanding of those requiring in-patient care.

Anyone who has had the experience of joining a group will know that it can at first feel very threatening, especially for shy and socially awkward people. This is how one parent described the parents' support group:

> *"I recognised the value of a support group but it took a great deal of courage to walk into a room full of people. I had already met the social worker and it helped a lot seeing a familiar face when I arrived. The group has helped me in many ways. I don't feel so alone now. No matter how sympathetic and understanding other parents might be only those involved with haemophilia can really understand all the problems that have to be faced."*

At first the parents' group shared with one another the personal biographies of their children and how haemophilia affected them. To talk about the children seemed "safe" but to talk about how they (the parents) felt was much harder. The coming together with "experienced" parents who were able to share personal feelings has been invaluable and many comments such as "Yes, I felt just like that too" or "I thought it was only me who felt that way," has helped to reassure parents that they are not alone, and that haemophilia can be survived.

SAFETY VALUE

Coming together with people experiencing similar situations can act as a safety valve. Just knowing that help is available and that others are concerned and care about you gives encouragement and reassurance. As a member of the carers' group said, "I did not feel anyone would be interested in my problems, how wrong I was." This has been borne out at every group when absent members are asked about with care and concern and one feels a strong sense of cohesion and support.

As with all groups, aims and expectations need to be considered and shared with all members from the outset. The groups all have different functions and initially it was important to spend time asking people why they had come and what they wanted from the group. Certain ground rules needed to be agreed upon, for example, the patients support group needed to know that confidences shared within the group would be respected and that no information would be shared without permission of the group member.

Groups can provide a 'safe' environment where trusting relationships can be nurtured. They provide a forum for sharing information and ideas of a practical nature. They can provide a strong feeling of cohesiveness and a sense of belonging. As members of the groups gain confidence in their ability to cope with their personal situation and their own feelings, discussions widen as they begin to look to the needs of others. As happened in the bereavement support group, members looked at ways of helping others not able to attend, perhaps because of distance or because they felt they could not face coming back to the hospital where the groups meet. We know that some people do find groups overpowering and prefer contact by individual visit or telephone. Members have been able to offer this support to others who have been bereaved, passing on their experience that grief can seem overwhelming and at times never ending, but that it is possible to get back to a normal kind of life again.

Group members have an opportunity to look at themselves and their relationships with family and friends. We all need to be allowed to express and consider these issues in a non-directive way. Groups have a great potential to 'heal'. The closer the trust shared by its members the higher the investment to help each other.

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Social Work Support

St Thomas' Hospital Haemophilia Centre now offers work support for HIV positive clients and their families, by way of counselling and practical assistance with DSS, Housing etc.

Appointments can be made by contacting the staff at the Centre, or by phoning Mike Van Dijkhuizen at St Thomas' Social Work Department on 081 922 8080 extension 154.

A TROUBLE SHARED

(Continued from page 13)

The sharing of feelings and emotions offers a unique opportunity to cut beneath social masks, and the care, help and support offered by group members to each other can be very therapeutic and rewarding. The companionship and opportunity to feel in touch with people who 'understand' can be a great incentive to explore and share ways of coping with life's troubles. Truly a trouble shared is a trouble halved.

The second person who inspired me to set up a support group was GRO-A 21-years-old, was in hospital for many weeks over Christmas with serious chest infections. He was experiencing many of the emotions, the feelings which are part of the process that people go through when trying to come to terms with their illness. Anger, fear, denial, resentment, depression, withdrawal and isolation, blame and guilt are but a few of the overwhelming feelings that can come pouring in and which can be muddled and change quickly. These reactions can vary from one person to another and this is quite normal. There is no right or wrong way to feel. GRO-A needed an outlet for his feelings. He missed his 'mates' from clinic, mates he could talk to openly and freely who would really understand. And so, with GRO-A 's help, the idea for a second support group was formulated.

Throughout 1989 a variety of groups have been established:

A parents support group for parents of young boys with haemophilia. The frequency of these meetings varies according to need. Parents have the opportunity to come together to share some of the common anxieties and concerns that bringing up a young child with haemophilia can present. We are often joined by parents of older children who come alone to share their experiences and to offer reassurance to new parents that life can be full, rewarding and very normal, even with haemophilia!

A bereavement support group which meets once a month. Members see their coming together as being of real value in providing positive goals towards which their combined sad experiences can be channelled. Although a small group, their interests and backgrounds are varied and all feel that their experiences mean they view issues and events from a new and perhaps clearer perspective. It is not a problem that we are all so different; what is a problem is when we have no opportunity to talk about it. Painful issues are aired and as one member stated, "it's such a relief to be able to talk about it (death), only those involved really understand".

A patients support group which meets every two weeks.

This group was started to enable patients attending regular clinics an opportunity to share experiences and feelings in a safe environment. Talking about sensitive issues is never easy. This is how one man describes the group:

"It's membership is exclusive but not enviable, for no-one would want to subscribe to the conditions (HIV) of membership. To be able to talk openly to people living with the same difficulties can be of enormous psychological help, to receive encouragement, ask questions and get answers from people who face the same problems such as health, family, home life, work and friends. It can be sad and depressing to see friends in the group become ill but the welcome and support offered to and by each member is invaluable. We have lots of laughs and have many words of encouragement to offer each other".

£1,800 boost for Hampshire funds

Hampshire Group's Centralised Banking Account benefited by over £1,800 from a three-day Christmas Fair held in November at Woodcote Manor, Bramdean. The organisers, Yvonne Hutchinson and Caroline McLaughlan, have run a similar function for a number of years, and we were delighted when they offered to divide the 1989 proceeds between ourselves and Rainbow Trust (which provides respite nursing and a hospice for children who are terminally ill).

Each day about 15 different stalls sold an amazing range of items from freezer cookery through jumpers, jewellery, china, books, cosmetics, hand painted nursery furniture to stocking fillers. Both charities ran their own stalls.

A mailing list of over 2,000 produced a steady stream of customers who were invited to purchase tickets for a raffle of prizes donated by stallholders. Local members helped with selling tickets and with paté and cheese lunches which went down well at £3 per head.

The bulk of the profits came from stallholders who donated 10% of their takings to the event. Going by the excellent end result they must have had a very good trade.

Many thanks to everyone for their hard work and generosity and especially to Caroline McLaughlan and her mother for the use of their lovely home.

(The picture shows Caroline McLaughlan presenting a cheque to Jane Hodgson of the Hampshire Group in the magnificent hall of Woodcote Manor.)

North West Group's A.G.M.

Over one hundred of the North West Group members turned up for the A.G.M. at St Elizabeth's Parish Hall in Aspull near Wigan on November 11 to conduct the usual A.G.M. business and to enjoy a talk on the North Wales Adventure Holiday from Dr. Tom Korn of Bangor Hospital. Dr. Korn's talk was greatly appreciated and tempted a few of the older members to ask when one was going to be organised for them.

The A.G.M. also doubles up as a social occasion, the bar and disco ensured that some good socialising took place; a very impressive buffet supper provided by the fair hands of Pauline Dawes and Anne-Marie Hartshorn kept everyone suitably fuelled and a good time was had by all.

The evening was marred temporarily for a few members – they got re-elected!

'FRANS HALS' EARLY VIEWING

Our picture shows GRO-A *presenting HRH The Princess Margaret with a bouquet at the Royal Academy early view of Frans Hals exhibition. Also in the picture are Michael Watson, Chairman of CRUSAID, and The Revd Alan Tanner, our own Chairman.*

This event was generously sponsored on our behalf by CRUSAID and we are most grateful to them and Geoff Henning their Director for allowing the Society to benefit from this event.

BLOOD TESTS – WHAT THEY MEAN

The medical evaluation of HIV-infected individuals is a complex and often difficult process. An important part of any complete evaluation is the interpretation of laboratory data. Laboratory data are used to help physicians decide when it is appropriate to initiate antiviral and other preventive therapy. Laboratory tests are also used to follow patients for clinical response to therapy and to monitor for potential side effects.

FULL BLOOD COUNT (FBC)

This is the 'routine' test that physicians order when they want to evaluate blood count. There are essentially three components to the FBC that deserve separate discussion: values pertaining to red blood cells (RBCs), white blood cells (WBCs), and platelet counts.

Red blood cells: RBCs are the cells that bring oxygen to all parts of the body. Normal RBC values for men are higher than for women. The RBC count is part of the FBC, but this is not the value that most physicians use in their evaluation; the level of haemoglobin is most often referred to. Anaemia is a condition where the RBC count is too low. A person with a low level of RBCs will have a low haemoglobin level.

Normal haemoglobin values for adult males are 14-18g per 100ml of blood. Normal values for infants older than two weeks and children vary with age but are generally 1-2g lower than adult female values, which are approximately 12-16g. People with HIV infection will often have lower than normal levels of haemoglobin whether or not they are on treatments that can lower RBC counts.

White blood cells: WBCs make up part of the immune system. Like other blood cells, they are produced in the bone marrow. The WBC count is expressed as the number of cells per cubic millimetre of blood. There is a wide range of normal values between approximately 4,500 and 10,500. People with HIV infection can have low WBC counts whether or not they are on medication that is toxic to WBCs. The total WBC count is the sum of different types of cells. The following types of WBCs are measured in the FBC; neutrophils, lymphocytes, monocytes and eosinophils.

Neutrophils are WBCs that fight against and prevent routine bacterial infections. They normally make up the largest percentage of WBCs in the circulation. In the FBC, they are expressed as a percentage of the total WBC count and are generally between 30% and 70% of the total. Generally speaking, when a person has an acute bacterial infection, the WBC will rise in response to the infection. The majority of this increase will be comprised of neutrophils. Patients with neutrophil counts under 1600 are considered 'neutropenic' and are at increased risk for bacterial infections. Those patients with counts between 1,000 and 1,500 are in a 'grey zone'. The neutrophil count can fall when bone marrow toxicity is caused by zidovudine (AZT), or other drugs.

Lymphocytes play a central role in proper functioning of the immune system. Lymphocytes are divided into T-cells and B-cells. The FBC values do not differentiate between types of lymphocytes. The main role of B lymphocytes (B-cells) is to produce antibodies. Generally speaking, 35-45% of the WBC is made up of lymphocytes. It is important to realize that a fluctuating WBC count does not necessarily mean that the lymphocyte count is rising or falling.

Monocytes make up a much smaller percentage of white blood cells – usually about 4%. Their relevance to HIV infection is not in their absolute numbers but in the fact that, after circulating in the blood stream, these cells settle in various tissues of the body and become macrophages. Macrophages are important reservoirs of HIV. It is believed that HIV enters the central nervous system (and the brain) through macrophages.

Eosinophils are specialized types of WBCs. People with certain medical conditions (i.e. allergies, parasitic infections) may have an elevated eosinophil count. They generally comprise approximately 2-5% of the total WBC count.

Platelets have a central role in assuring proper blood clotting. An absolute number is obtained in the FBC. The platelet count can vary widely. Generally speaking, any value between 140,000 and 350,000 is considered normal. HIV infection can cause a lowering of the platelet count. This can occur at various stages, including early stages of infection, and does not necessarily correlate with a deterioration of immune function.

Generally, one is not at increased risk for significant bleeding with platelet counts above 40,000. Bruising can be evident at higher counts, and some people with HIV infection can have much lower counts without evidence of bleeding. There are several different therapies that can be used to raise the platelet count.

LIVER FUNCTION TESTS

When liver function tests (LFTs) are performed, the physician is essentially looking at the levels of certain enzymes that are present in liver cells. With liver inflammation, or death of cells in the liver, there is an increase in blood levels of these enzymes. Many different viruses can cause inflammation include the hepatitis viruses, cytomegalovirus and Epstein-Barr virus. Alcohol and certain drugs can also cause inflammation, with subsequent elevation of liver enzymes.

Any increase in liver enzyme levels is considered abnormal. However, many people have chronic mild elevation of their liver enzymes which then become a 'normal baseline' level for them, due to previous or ongoing medical conditions. Many medications are metabolized in the liver. For this reason, LFTs are monitored in people who are on certain medication including AZT, intravenous pentamidine, ketoconzole, and other drugs.

T-CELL TESTS

T-cells are one of two types of lymphocytes (WBCs) named after the organ from which they were believed to originate (in the case of T-cells, the thymus). T-cells are divided into two main subsets which differ significantly in immune-related function. T4 cells, also known as helper T-cells because they play a central role in signalling various components of the immune response, are the major target of HIV. Infection of T4 cells can lead to the destruction or dysfunction of these cells with subsequent disruption of proper immune function. T8-cells are also known as suppressor T-cells since they downgrade or "turn off" the immune response. Suppressor cells are important in the normal functioning of the immune system since they act as a safety valve against constant immune activation and stimulation which can cause significant tissue damage. A normal immune system functions best when there is a proper balance between these two types of cells so that the immune system responds to a foreign threat (i.e. an infection) and then 'turns off' when that threat is removed.

MEASURING T-CELL LEVELS

There are three T-cell values that physicians can look at in evaluating immune functions: T4 to T8 ratio, T4 percentage of all T-cells and absolute T4 count. People with normal immune function have a ratio of T4-cells to T8-cells of two to one. People with HIV infection usually experience a lowering of this ratio, and it is not uncommon for people with HIV infection to have ratios of less than 0.5. This occurs since there is destruction of T4-cells and an increase in T8-cells. Ratios can vary in the presence of infections.

There is also a wide range of normal absolute T4 counts. A normal value is anything above 500. Counts can fluctuate from laboratory to laboratory, also fluctuations can occur during the day.

As a general rule, the lower these three values, the more immunocompromised the person is. With HIV infection, these values usually fall over time (years). Most current clinical trials use absolute T4-cell numbers as an inclusion criterion. All of the above indices have prognostic value; but specifically, an absolute T4 count below 200 is associated with development of HIV-related symptoms and opportunistic infections. Adults with T4 counts greater than 200 probably will not develop severe opportunistic infections. The higher the number, the less likely the development of an opportunistic infection.

SERUM p24 ANTIGEN

HIV is composed of different protein and glycoproteins (proteins plus sugars). These proteins are named according to their molecular weight. They are called antigens since they stimulate an immune response. p24 is an HIV core protein with a molecular weight of 24,000. There are many proteins and glycoproteins in HIV that induce antibody responses. These antibodies are generated by B-lymphocytes.

p24 antigen can be detected in the blood when cells in the body are actively producing virus. We know from studying the natural history of acute HIV infection that circulating antigens can usually be detected in the blood starting within two weeks of infection. The

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BLOOD TESTS – WHAT THEY MEAN

(Continued from page 15)

body will usually then mount an antibody response directed at the antigen; and, generally within 3-5 months of infection, the antigen will disappear. It is thought that, at this point, the virus lies latent in infected cells. This stage can last for many years. At some point, for unclear reasons, the virus is stimulated to reproduce, leading to the presence of HIV antigen in the serum again. This is what is detected with the p24 antigen assay.

p24 antigen levels have been shown to be associated with an increased likelihood of developing HIV-related symptoms. It is a marker that is often followed in patients on experimental therapy, to monitor disease progression. Loss of p24 antigen levels in patients on antiviral therapy is considered a good sign, since the implication is that the level of viral replication in the body has diminished. At the present time, the p24 antigen assay is not available commercially and is being used only as a research tool.

HIV-infected individuals produce antibodies to p24, which neutralize the protein. A high level of p24 antibody correlates with a protective effect against progression of disease. A rapid decline or loss of p24 antibody may signal imminent danger of progression.

PCR (POLYMERASE CHAIN REACTION)

The PCR assay is an extremely sensitive test which detects tiny amounts of viral RNA that have been incorporated into blood cells. It is a test that can be used to document HIV infection prior to HIV antibody production. It does not require active HIV replication with presence of virus in the blood to be positive. The PCR assay is a useful test for the diagnosis of HIV infection in infants born to HIV infected women. The ELISA and Western Blot antibody tests cannot be used to establish a diagnosis of HIV infection in infants in their first year, since antibodies pass from the mother to the baby through the placenta. A positive antibody test may be a reflection of maternal antibody status, not necessarily infant infectivity. Infants who are actually infected with HIV, however, should have a positive PCR. At the present time, this test is a research tool and is not commercially available.

BETA-2 MICROGLOBULIN AND NEOPTERIN

Beta-2 microglobulin (B2M) is a small protein that is present in most cells of the body. It is a marker of inflammation; elevated levels are believed to indicate increase cell turnover. Elevated levels of B2M has been shown to correlate with progression of HIV infection. Asymptomatic people with elevated B2M levels are statistically more likely than those with normal levels to develop AIDS within a shorter period of time. Normal values can differ slightly depending on the laboratory. It is a useful test in helping the patient and physician decide how aggressively to pursue various treatment options.

Another market that has been shown to correlate with an increased risk of disease progression is neopterin. Activated macrophages release a large amount of neopterin; they are probably the source of elevated neopterin levels in active HIV infection. Neopterin levels have been shown to correlate inversely with T4-cell counts; as T4-cell counts fall, serum neopterin levels rise. However, neopterin levels should not be considered a replacement for T-cell studies at this time.

Source: Treatment Issues. 5 December 1989.

THE EUROPEAN CONSORTIUM

As 1992 draws nearer there is an increased awareness of our need to work closely with our colleagues in other European countries. This was emphasised by a recent meeting of the Consortium held in Vienna, hosted by the Austrian Society and attended by delegates from seventeen European Haemophilia Societies.

The UK continues to co-ordinate the Group and we were represented at the Vienna meeting by Jonathan Cooper and David Watters.

THE LONDON MARATHON

We are proud to report that GRO-A completed the London Marathon in 4 hours 16 minutes. We congratulate him on this splendid achievement – now it's over to you!! We look forward to receiving your sponsorship monies as soon as possible so that GRO-A might know how much we all **really** appreciate what he has done for us.

CONTACT LIST FOR LOCAL GROUPS

In order to establish contact with your local Group you should WRITE in the first instance to the Group which appears to be nearest to you – your local Haemophilia Centre will also have knowledge of your local Group and the contact person there.

BIRMINGHAM:
Mrs W Ryan,
18 Rupert Street,
Wolverhampton,
WC3 9NS.

CAMBRIDGE & DISTRICT:
Mrs C Brooks
Old Close, Hockerhill School
Dunmow Road, Bishop s Stortford,
Herts CM23 5HX

CORNWALL
W R Gough
3 Bonython Drive
Grampound
Truro TR2 4RL

DERBY:
Mrs. E. Hatton,
Dovecote Flat,
Melbourne Hall,
Melbourne,
Derbyshire,
DE7 1EH.

EAST KENT:
Mrs. G. Jolley,
6 Millstream Close,
Faversham,
Kent,
ME13 7SA.

HAMPSHIRE:
Mrs. M. Clark
30 Belmont Grove
Bedhampton
Havant PO9 3PU

JERSEY:
Mrs P Fosse,
12 Beech Crescent
St Clement,
Jersey.

LEICESTER & RUTLAND:
Mrs D B Gilmour
10 Aintree Crescent
Oadby
Leicester LE2 5GD

LEWISHAM (South London):
Mr GRO-A
147 Wellmeadow Road
Catford
London SE6 1HP

LINCOLN & DISTRICT:
Mrs. S.L. Cook,
50 Southfields,
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LN4 2

MERSEYSIDE:
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6 The Tamneys,
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NORFOLK & NORWICH:
Mr G Hazlewood
Wellgreen View
4 School Road, Frettenham
Norfolk NR12 7LL

NORTHAMPTON & DISTRICT:
Mrs. R. Shaw
23 High Street
Great Houghton
Northampton
NN4 0AF

NORTH EASTERN
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54 Shaftesbury Avenue
The Roundhay, Leeds LS8 1DT

NORTHERN:
Mrs D S Frame,
22 Awnless Court,
South Shields,
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NE34 0XR.

NORTHERN IRELAND:
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16 Spirehill Road
Hillsborough
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NORTH WALES:
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NORTH WEST:
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NOTTINGHAM:
Mrs P Goddard,
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Treboeth,
Swansea,
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47 Seaforth Avenue
Southend-on-Sea
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SOUTH WALES:
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16 York Place, Risca
Newport NP1 6FR

SCOTLAND:

Grampian
Mrs C Robertson
37 Cummings Park Crescent
Aberdeen AB2 7AS

Perth
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Nutritional guidelines for people with HIV

Ideal nutritional care begins with a complete assessment by a dietitian. Such assessments involve studying eating habits, personal food preferences, and calorie and nutrient intake, and then developing guidelines for what patients should be eating. Nutritionists have started to conduct these assessments at earlier stages of infection so that asymptomatic individuals may develop proper nutritional habits.

In developing a diet, providers must be aware of nutrients that are important for people with HIV infection, the food sources of those nutrients, the preparation of these foods, and the HIV-related conditions that may complicate obtaining adequate nutrition. In addition, health providers must consider different cultural and family traditions that surround food and eating, and, in order to ensure compliance with strict regimens, nutritionists should develop diets that honour individual food preferences.

NUTRIENTS

In general, recommended diets for people for people with HIV infection include high amounts of protein, a steady intake of calories, and sufficient amounts of vitamins and minerals. Foods high in protein – meats, rice, dairy products, fish, nuts, peanut butter, eggs and beans – are generally better sources of calories than are foods high in fat alone. Fat, however, is a good source of calories, a characteristic that is particularly important when patients are experiencing rapid weight loss or are consuming an insufficient number of calories. For patients who get insufficient amounts of protein in regular diets, nutritionists may recommend special high-protein and high-calorie beverages. These drinks may be taken between meals and are especially useful for patients unable to eat solid foods.

Proper vitamin and mineral intake also is important to a diet. Patients consuming large quantities of vitamin or mineral supplements should be monitored. A daily vitamin-mineral supplement that provides 100% of the recommended daily allowance of several vitamins and minerals is not considered harmful and is recommended for those whose diets lacks these essential nutrients.

The following are important vitamins and minerals, and good food sources for them.

- Iron is found in meat, poultry, egg yolk, whole grain breads, cereals, dark green vegetables, nuts, bran and dried fruits. Iron supplements are not advised without professional guidance.
- Zinc is found in seafood, beef, liver, yeast, wheat germ, cheese and whole grain foods. It is needed for maintaining immunity and in metabolizing carbohydrates.
- Selenium is found in seafood, brown rice, bran, kidney, onions, milk and nuts.
- Vitamin A is found in green and yellow fruits and vegetables, live, fortified milk and other dairy products and eggs. Exceptionally large doses may be toxic.
- Vitamin B is found in cereals, wheat germ, rice, yeast, fruit, beans and pease. Riboflavin is helpful in maintaining mucosal barriers essential to the body's defences.
- Vitamin C is found in citrus fruits, tomatoes, melons, broccoli, strawberries, fresh potatoes and green leafy vegetables. Some physicians have recommended large doses of vitamin C. Excessive amounts, however, can cause kidney stones and diarrhoea.
- Vitamin E is found in vegetable oils, green vegetables, wheat germ, meats and eggs. Deficiencies can lead to muscle wasting and gastrointestinal disease.

People with HIV infection must avoid some foods and food preparations that may transmit infectious bacteria. Nutritionists recommend that patients thoroughly wash products, especially lettuce and other green vegetables, with warm water; keep eating and cooking areas clean; cook meat well; avoid raw fish or raw eggs; and use only pasteurized dairy products.

NUTRITIONAL IMPLICATIONS OF HIV-RELATED CONDITIONS

People with HIV infection may eat less because of the adverse effects of medication, the effects of other diseases, or a lack of appetite. Anorexia, nausea and vomiting, bowel disease, and neurological diseases may also lead to lowered food intake. In addition, mouth pain and sores, swallowing problems, and dulled taste sensations can make eating difficult. The following are guidelines to handle common gastrointestinal symptoms:

- Anorexia can result in a decline in body weight, fat and cell mass. To detect anorexia, health providers should monitor body weight and calorie intake, and devise diets that meet personal tastes. Nutritionists recommend: small, frequent meals with high-calorie foods; high-protein, high-calorie liquid formulas; and, if these interventions are insufficient, tube feeding.
- Oral and oesophageal complications, including oral candidiasis and Kaposi's sarcoma lesions, may cause difficulty in chewing or swallowing. Drinking fluids with meals can improve the ability to chew and swallow. Foods served at room temperature are also easier to handle.
- Bowel disease and diarrhoea may be treated by ingesting liquids, caffeine-free foods and beverages, and low-lactose foods, such as aged cheese and cultured yogurt. Foods should be low in fat and in fibre, for example, white rice, white bread and cooked fruits and vegetables with the skin.
- Nausea and vomitting are often caused by medications, and may be treated with clear, cool beverages, clear soups and foods with little aroma.

It may be necessary to use alternative feeding routes for patients who cannot be fed orally. Parental feeding may be effective for some individuals; however, nutritionists generally recommend intravenous feeding be used only when a patient's digestive system is unable to handle food. If possible, alternate forms of enteral feeding, for example special oral formulas or tube feeding, are preferred.

Source: *FOCUS*, January 1990

AIDS MASTERY

People who are interested in exploring HIV and how it affects their lives might be interested in The AIDS MASTERY.

The AIDS MASTERY is a three day workshop open to people with AIDS/ARC/HIV, their friends and loved ones, and to people working in the field either on a voluntary or professional basis.

Through a variety of individual and group exercises the AIDS MASTERY explores the personal and emotional challenge that AIDS presents. The purpose of the workshop is to discover ways in which we can live fully, creatively and powerfully in the present, having our lives be about living rather than the fear of dying.

For further information contact:
Remi Easom
Robert Hale
Jon Varker-
Littlewood
GRO-C
GRO-C
or write to BM BREATHE, LONDON WC1N 3XX.

NATIONWIDE RESEARCH TRIAL ON DDI OPENS

by Nick Banton (Body Positive Newsletter)

March 1990 saw the launch of two new and importants research trials in this country into DDI, one of the most talked about new antiviral drugs, to see if it's effective in combatting HIV.

DDI – A BACKGROUND

DDI (Dideoxyinosine) is a drug which acts against HIV in a manner similar to AZT (Zidovudine), i.e. it apparently limits the reproduction of the virus without stopping the virus' action altogether. Scientists do not know, however, if it is as effective or more effective than AZT. Much probably depends on their relative toxicity: the winner might be the less effective drug if it could be proved to be significantly safer and therefore able to be given in much higher quantities.

While laboratory studies suggested that DDI was less dangerous to human cells than AZT, human trials have shown that DDI can be toxic, even if the toxicities first reported were reversable.

While researchers are still unable to decide on DDI's long-term effectiveness, which is the major question for many people, the initial studies did show that the side-effects of DDI are different to those of AZT. The main side-effects of DDI seem to be peripheral neuropathy (pain or loss of feeling in the limbs) and inflammation of the pancreas. Therefore people who are unable to take AZT because of anaemia or other related toxicities may be still able to benefit from antiviral therapy if they can tolerate DDI.

DDI went through small scale tests for toxicity in the USA last year, as a result of which the US government agreed to make the drug widely available under a so-called "compassionate release" programme in mid 1989 (for details of the American research and release programme, see the BP Newsletter 76, 29 August 1989). There have been various problems, however, with the way in which DDI was made available in the USA. Given the restrictive nature of criteria for inclusion in the government trials and the widespread availability of DDI on "compassionate release", very few people have signed up for the official trials (reportedly only 300-odd compared to over 4,000 in the compassionate release programme). This means that it will take a long time before we can establish any hard data on how safe and how effective the drug is, especially if we want to compare it to taking another drug such as AZT, or taking nothing at all.

This is particularly worrying because the latest reports from the USA suggest that DDI's side-effects may be more serious than once realized. According to these press reports, seven people in the USA are reported to have died from side-effects of DDI, in particular pancreatitis leading to kidney failure. In such circumstances, it is important to know more. How sick were the people taking DDI in the first place and is this seven out of a few hundred or seven out of a few thousand?

THE UK TRIALS

There are two trials now underway in the UK. Both focus on evaluatiung the value of the new drug for people intolerant of AZT. People participating in either trial can be sure of obtaining DDI if they wish to do so.

One, a single hospital study in London which is being sponsored by the manufacturing company Bristol Myers Squibb, has been strictly designed to decide whether DDI is fit for licensing on this country. This is a so-called "open label" trial, in that all the participants have the relevant information as to the drug and how much of it they are taking. People have already begun taking DDI through this programme.

The second, a multi-centre study under the auspices of the government-funded Medical Research Council, will test the safety and effectiveness of DDI on people considered to be intolerant of AZT. As this trial is the one to which more people throughout the UK will have access, the rest of this article will concentrate on it. The study has two arms, each of which has a series of options.

a) a comparison of DDI at high dose (375mg twice a day) or low dose (100mg twice a day)
b) a comparison of high dose DDI, low dose DDI and no drug at all.

While participants can choose in which of the two arms a) or b) they participate, they will not know to which of the options within that arm they have been assigned. Participants will be randomly assigned to one of the options and neither they nor their doctor will be informed as to which dosage within that arm they are taking.

The aim of this study is to study both the relative effectiveness of two different dosages of DDI for people who feel that it is definitely better to take DDI than to take nothing and also to study the relative benefit of DDI versus placebo in people who are less convinced about the overall value of the drug. Clearly the people entering the two different arms of the trial will be quite different, but – with proper pre-trial evaluations – this should not affect the result. Therefore the placebo arm is optional. Anyone who enters the trials to obtain DDI can do so.

The overall goal of the study design is to obtain good information on safety and effectiveness as promptly and ethically as possible. In this it is an excellent example of good practice and it has developed a compromise to satisfy both the needs of researchers and people with HIV and AIDS.

WHO CAN ENTER?

The trial is for people considered to be intolerant of AZT. "Intolerance" is a relative concept of course and the inclusion criteria have been developed to allow doctors, acting presumably in conjuction with their patients, to make flexible decisions on intolerance. The researchers have estimated that there are some 300 people in the UK who qualify for entrance in the trial. As the MRC study is to operate in partnership with a similar study in France, and possible other European countries, the overall number of people testing DDI will be high enough to generate good results relatively quickly.

As the MRC has access to the bureacracy and the standardized laboratory testing of the previous AZT Concorde study throughout the UK, it will allow people from a much wider geographical range than usual to participate in this important research.

FUTURE TRIALS

Everyone accepts that we want to know more about DDI and that this information is urgent. If initial results confirm a low rate of toxicity for DDI, it would be sensible to begin trials comparing its effectiveness together with, and instead of, AZT. The Medical Research Council's researchers are said to be already discussing such plans, but they would need not only several more months planning but also good early results from the trials beginning now before they can go ahead.

FUNDING THE BULLETIN

We're very grateful to Armour Pharmaceutical who are helping with the funding of The Bulletin this year. In our picture their managing director Chris Bishop is seen handing over a cheque for £10,000 to David Watters.

DON'T BE ASHAMED

Sir:
Just a few lines to let you know, that my recent claim for MOBILITY ALLOWANCE has been successful.

As you can imagine I am very pleased especially as it was the first attempt. However I am very concerned, that a lot of people with haemophilia I spoke to at the recent "Blackpool Weekend" seem to be ashamed at applying for Mobility Allowance, and I can"'t help feeling that they should be made aware, that they cannot expect help if they are not prepared to help themselves, by doing so are opening the door to ALL those with haemophilia, because I think we should all be made aware of the times people do not see us suffering in pain (including doctors).

However may I take this opportunity of thanking you all for your help.
Yours etc.
Grateful
Manchester

THANKS

Sir:
Thankyou for a great weekend at Newcastle. Out of all the women I was talking to each, had got something out of it and all were going home with renewed strength and hope.

The group that I was leading derived great benefit from the weekend and I got the impression that this was just the beginning.

I came away knowing that a lot of women had been helped by the people that led each workshop, many friendships have been forged, names, addresses and telephone numbers exchanged and women felt that they were not on their own.

I know it costs a lot of money but please think of those that did not benefit from a weekend such as this.

Please pass on from my regional group our thanks to Heather, Linda, Jane and Caroline for all the hard work they did to get the weekend together and to the Haemophilia Society for funding.
Yours etc.
A Member

HELP WANTED

Sir:
I am the 36-year-old wife of a 46-year-old with haemophilia who is HIV positive.

At the moment I am involved in writing a book about coping with the HIV infection, based on my own experiences over recent years.

It struck me that there may be others who would like to share their experiences with me and thereby give me a broader view of how others are dealing with this problem. I am particularly interested in learning of ways in which people have developed a positive approach to HIV.

Please be assured that any communication will be as confidential as you wish it to be, and that any comments received will only be included with permission.

If you feel able to contribute, please write to me c/o David Watters, who will pass on any letters.
Yours etc.
Mrs GRO-A

EXCHANGE

Sir:
My son, GRO-A, is a 15-year-old boy; he has severe haemophilia A. He has been learning English at school for the past three years, but he needs some practice in situations.

I would like him to live for three of four weeks with an English family, but I prefer to send him to a family like us (my wife and I are doctors).

We would be happy to arrange a return holiday.
Yours etc.
Further details from GRO-A, at the national office.

AND MORE THANKS

Sir:
I would just like to take this opportunity to thank the Society for the brilliant book you recently sent to us regarding the story of the GRO-A family. We all found it to be very interesting and also very helpful. It relates so well to our own family.

Once again I thank you for your lovely gift.
Yours etc.
Mrs GRO-A
Merseyside

THEY THOUGHT WE WERE HITTING OUR CHILD

Sir:
Thankyou for the copies of The Bulletin, which I read from cover to cover.

I have a daughter of six who has Von Willebrand's Syndrome. She loves music, plays the piano and sings. She fell of a horse once and is now wary of most of the things that other children her age do. She is always indoors, playing her flute (not too well!) or can be found with a pencil and paper drawing or writing stories.

I must say that we have had tremendous support from our Centre Director. Last year our daughter received some heavy bruising on her legs and when she got to school they contacted the social worker, who in turn contacted our GP – who was furious because our daughter didn't have as much bruising as he was led to believe.

I contacted my Centre Director, who helped us through this ordeal. It was heart-breaking to think that somebody thought we were hitting our only child.

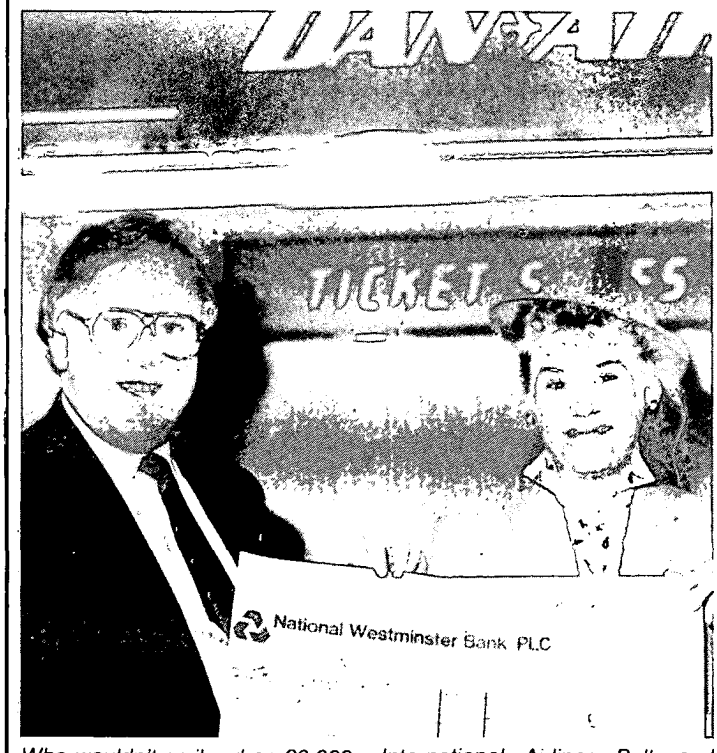
It is very comforting to know you have someone like the Centre Director and his team behind you. This might sound silly, but this is the first time I've been able to speak about this sad episode. It brings tears to my eyes and an ache to my heart.

My heart goes out to all those families who have been through what we went through. I'll never forget sitting in that cold hallway while the Committee (so-called) were passing judgement on us as parents.

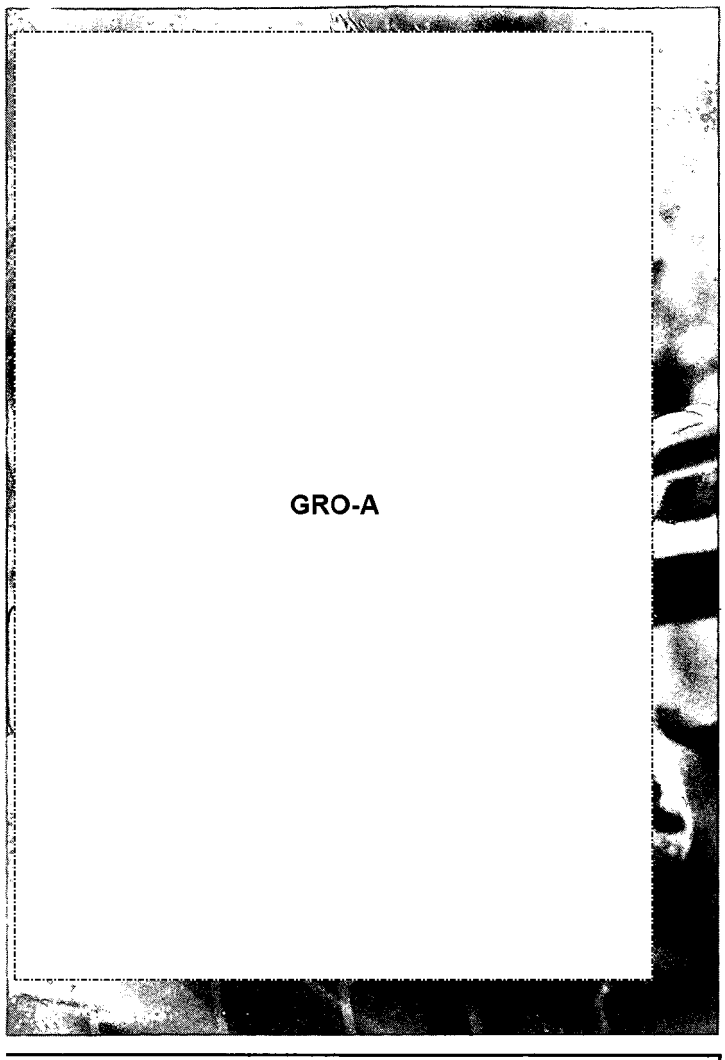
They apologised for their action and assured us it would never happen again. "After all, we had to make sure," said a health visitor.

It's a year now since it all happened yet I cannot bring myself to school for coffee mornings or meetings. My husband goes. I don't blame the school, but feel that somebody thought for one moment that we were abusing the child we live for.
Yours etc.
Mrs GRO-A

THANKS TO THE AIRLINES



Who wouldn't smile when £9,000 is being handed over to charity! Nikki Rayner of Dan-Air looks delighted to be handing over this cheque, the proceeds of the 1989 International Airlines Ball, and David Watters looks equally delighted to be accepting the magnificent sum on the Society's behalf.



Hot-shot GRO-A sets his sights high

GRO-A s aim has always been to keep active and not let his haemophilia rule his life. And keeping this positive attitude well in his sights is one of the reasons for his success in the fiercely competitive world of rifle shooting.

Winning his class in this year's UK championships with superior scores envied by many an able-bodied competitor and shooting his way, with son GRO-A to win the Birmingham Bell-target 'pairs', are recent successes topping up a shooting career that began in 1958 when he was first introduced to the sport.

It was ironic that he won a solid silver ice bucket for his UK championship triumph because GRO-A who will shortly retire on a total disability pension from local GRO-A based Land Rover Ltd, is one of those who have bravely survived the early daunting days when treatment for haemophilia was virtually unknown.

"In my young days it was 'rest' that was deemed to cure my aches and pains, and we slapped on cold compresses while I'd try to ignore the pain," he explains. "We didn't have a fridge, so my cold compresses were just cold tap water as we didn't have any ice cubes. Now I've got the ice cubes, and a fantastic ice bucket, but many knees are beginning to let me down as the damage was done in those early years."

He's had an operation on his left knee which he says has "done a lot of good", but left a joint a little weak.

GRO-A was born in Birmingham and went to school in GRO-A until he was 16, when he moved down to Lord Mayor Treloar College for three years. He still maintains regular contact with Treloar school pal GRO-A

For most of his life he has been employed as an electrician working at various times on radios and televisions, refrigerators, vending machines and for nearly 14 years with Rover on cars and trucks.

GRO-A is married to GRO-A, who is an auxiliary nurse, and they have two sons GRO-A (18) who works as a surveyor and GRO-A (16) who is still at school and is looking forward to joining the Royal Marines.

According to GRO-A GRO-A is as keen on shooting as his father, but GRO-A 'can't stand the sight of guns'.

Just six years after taking up the sport GRO-A was competing in 1964 with the country's able-bodied best in eliminators for the Tokyo Olympics. He didn't make it then, but is currently on the short-list for the World Games next month (June), eventually to go to the Barcelona Paralympics in Spain in 1992 with various other important competitions along the way.

He shoots the .177 air-rifle and his German gun (left-handed by the way), plus a .22 calibre rifle, cost £1,500, but were kindly donated by Homer of Worth Ltd. GRO-A has also had donations from the Society.

To compete against the rest of the world and be there with a chance of winning takes a lot of practice and a great deal of travelling – and of course costs money, so GRO-A would welcome any help he can get.

The .22 calibre shooting is done at a variety of distances but the Bell-target competition is fascinating. Shooting from six metres competitors have to place their shot through a minute hole in the target. If they are successful their slug strikes a 'bell' with a pronounced ring.

He wears his Haemophilia Society t-shirt at all competitions and makes this offer to any person with haemophilia who wants to know more about the sport. "It's a very satisfying pastime," he says, "and if there is anybody who would like advice on how to take up the sport I will be only too pleased to help. Furthermore, if there are any youngsters who would like tuition I will do it quite happily. I belong to several clubs where I can arrange facilities.

GRO-A s message is quite clear: "Don't let your haemophilia be a handicap, shooting is a sport where you can compete on equal terms. In case you're worried there is no kick from the guns. Dare I say it – Give it your best shot!"

FUNDS FROM THE MIDDLE EAST

Even in faraway Abu Dhabi people have been raising funds for haemophilia. In this picture Stewart MacGregor hands over a cheque for £1,750 to Martyn Clark, treasurer of the South East of Scotland Group, raised by a sponsored head-shave on the island of Das, where Stewart is firemaster. Stewart's young son GRO-C and other members of the family complete the picture.

THE SOCIETY'S NEW TELEPHONE NUMBER AS FROM MAY 6, 1990

071-928-2020

PUBLICATIONS

The following are available from the office:

Treatment Survey report 1986.
Teaching Boys with Haemophilia
Introduction to Haemophilia (3rd edition).
Treatment of Hemophilia. (Series)
International Haemophilia Cards (all you need for international travel).
Childrens Haemophilia Book.