Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392146

The Bulletin

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

Member of the World Federation of Hemophilia
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AIDS is one of the most pressing problems which the Society has ever experienced and it is comforting to know that we are now to have some additional help from the Government in dealing with this difficult situation.

NEW FUNDS TO FIGHT AIDS

£90,000 FOR REFERENCE CENTRES

The six English Haemophilia Reference Centres have been given £90,000 by the DHSS as part of new funds provided to fight AIDS. The £90,000 is earmarked 'for counselling', and on top of this the Haemophilia Society gets £32,000. These new funds have been described as a "one-off" payment.

The Haemophilia Society has welcomed the announcement as a first, although small, step towards the proper development of the Reference Centres' response to their new AIDS-related responsibilities.

HTLV-III antibody testing has placed an additional burden on these Centres not only in terms of an extra clinical and laboratory workload but also because they must now provide continued counselling and support to their patients in a constantly changing medical and information environment.

NEW APPOINTMENTS

The major Haemophilia Centres are now so poorly provided for, especially in terms of 'nurses', counsellors and social workers, that new posts will have to be created and counsellors, expert in haemophilia, appointed and trained. How this can be dne on the basis of funding for only one year remains to be seen!

The picture regarding extra funding for the Society is much clearer. £32,000 has been given to the Society, of which £12,000 was allocated by the DHSS to a conference on AIDS for health care professionals which will be held in Newcastle in early 1986.

FOR ADVICE WORK

The remaining £20,000 was given for 'advice work'. The Society has already been active in providing up-to-date factual information on AIDS through Haemofact and other publications such as Dr Peter Jones' Aids And the Blood - A Practical Guide and the Haemofact Special Edition - Advice on Safer Sex. Haemofact has been especially important as a means of providing information to members in order to allay the anxieties caused by the, often inaccurate, publicity which AIDS attracts.

Whenever an AIDS related news story breaks there is a flood of telephone enquiries which must be dealt with by our office staff. In addition to these

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£2,000 RAISED IN A WEEK

Pictured at the charity shop are many of the willing helpers, including Pat McAughey (fourth from left), Thomas McAughey (fifth from left), Mary Edward, group chairman (sixth from left) and John McAughey (extreme right).

Prowling around the shopping centre of beautiful Perth, and noting the activity centred on the cancer relief shop led Tayside group's John McAughey to the simple conclusion: 'Anything they can do, we can do . . . '

And so they did. He discussed the outline project of a charity shop for haemophilia with his wife Pat . . . and the idea became fact and figures, in fact £2,012.37p.

"We had tremendous co-operation from all sorts of people," explains Pat.

"Getting hold of shop property is difficult at the best of times, but the local Co-op let us have space at Scott Street rent-free.

"We had to pay for insurance, but free advertising in local newspapers and on Radio Tay for donations of goods resulted in a fantastic array of everything from a needle to an anchor."

They ran the shop with an average of 10 people helping every day.

"It's the largest sum we've ever raised, and we'd like to run it more often. However, it's not every week you can get a rent-free shop in a prime position," points out Pat.

"We feel sure the experience will benefit us for future use!! A big "thank you" to everyone who helped make it a success".

STOP PRESS

As this 'Bulletin' went to press the Government announced that a total of £270,000 would be made available to the six Haemophilia Reference Centres in England for specialist counselling of people with haemophilia to continue into 1986. The article on this page refers to the starter funding of £90,000 given for the last quarter in 1985.

It is not yet clear whether this allocation will be repeated in future years. It should be. Nor is it clear exactly how the Centre directors propose to make counselling available. There will be more news soon. Watch your Haemofact! With £45,000 allocated to each Centre we hope that sensible provision will be made for everyone with haemophilia within each Centre's area.

GENETICALLY ENGINEERED FACTOR 1X

Factor IX is required for the treatment of patients with Christmas disease (haemophilia B) and we all recognise the need for a purer product, especially one that is guaranteed free of the AIDS virus as well as other less serious but still debilitating viruses such as hepatitis.

The promise of a genetically-engineered factor IX has been on the horizon since the human gene was first cloned in 1982. Now three independent scientific reports, one from the University of Oxford and two others from overseas biotechnology companies, show that small amounts of human Factor IX can be synthesized in the laboratory using a modified Factor IX gene and a variety of cell types of mammalian origin as a "factory".

Differing yields (in the order of one-millionth part of a gram) are reported, but in all three cases there is no doubt that the Factor IX made will substitute for normal Factor IX in laboratory clotting tests. As it is produced under controlled laboratory conditions from materials not isolated from human blood, it should be free of the AIDS virus.

What remains to be done is to produce pilot scale amounts of Factor IX at high purity and test the material rigorously for its similarity to blood-derived Factor IX in various biochemical and animal studies. These are necessary checks before material is tested clinically in humans.

Another serious complication of treatment of patients in addition to AIDS, is the development in 1% or so of patients of specific anti-Factor IX antibodies. We must therefore ensure that genetically engineered Factor IX is not recognised by our immune system as "foreign" so as to avoid increasing the numbers with this complication.

Because relatively large amounts of Factor IX are needed (I estimate that for 950 or so patients in the U.K. this is at least 50g per annum), it is also important to maximize the yields of genetically engineered Factor IX on a small scale before attempting large scale production.

This, as well as the large scale fermentation technology required to culture the mammalian cells, will obviously require further development work. I am optimistic that this will proceed quickly, hopefully in this country, and that a better product will be available for patients in the not-too-distant future.

The following are the reports in "Nature" (found in reference libraries) for those who require more detailed information: (1) Anson D S, Austen D E G and Brownlee G G (1985) Nature 315, 683-686, Expression of active human clotting factor from recombinant DNA clones in mammalian cells. (2) de la Salle H, Altenburger W et al (1985) Nature 316, 268-271, Active y-carboxylated human factor IX expressed using recombinant DNA techniques. (3) Busby S, Kumar A et al (1985) Nature 316, 271-273, Expression of active human factor IX in transfected cells.

G G Brownlee
Professor of Chemical Pathology

NEW FUNDS (Continued from Page 1)

calls our Co-ordinator estimates that the Society has dealt with some 400 Press enquiries in the last six months. As a result the Society has already had to make organisational changes to cope and will continue to respond as needs arise. For example this month (December) we have introduced a 'Newsline' service providng daily recorded updates on news stories of concern to people with haemophilia.

The Society's concern for proper counselling provision to be made in Haemophilia Centres has led it to co-operate with St. Mary's, Paddington (which runs the AIDS counselling training courses for all Regional Health Authorities) with the object of establishing courses specifically tailored for haemophilia workers.

On a related topic, members may recall that the Society has already provided funding to the Public Health Laboratory Service (PHLS) and the Middlesex Hospital (where all HTLV-III tests are evaluated) so that in the absence of other financial support they may continue to monitor the antibody status of people with haemophilia.

In the DHSS announcement of September mention is made of the redevelopment of the Blood Products Laboratory at Elstree which 'should ensure our self-sufficiency in blood products by the end of 1986'. The Society naturally hopes that the end of 1986 will prove to be a realistic date. As members will be aware self-sufficiency has been promised 'soon' since 1976.

At the invitation of the Blood Products Laboratory, Society representatives now make bi-monthly visits to Elstree and have been impressed by both the new building and with the determination shown by the BPL staff, at least, that the UK will become self-sufficient in blood products.

We sound a note of caution here because self-sufficiency ultimately depends on the ability of the Blood Transfusion Service to provide enough plasma for Elstree to turn into concentrates. In the past the Transfusion Service has not been able to meet the demand for plasma and now it faces new AIDS-related problems which may reduce, rather than increase, the supply of donated blood.

Points of View

A Question of Counselling

Sir:

I do not think that my correspondence with Dr. Winter can be concluded to the satisfaction of both parties. However, I do not see much point in becoming embroiled in lengthy and profitless argument, and will therefore be as brief as possible.

First, I did not quote from the international study on the facilities of genetic counselling in haemophilia to *justify* the views of the Genetic Counselling Group at the Bournemouth Seminar but to comment on them.

Secondly, Dr. Winter misuses some figures from our study of patients' views of genetic counselling to argue that our conclusions are based on a hopelessly inadequate sample. He has taken the figures out of context while their true significance is very different.

Thirdly, it was true both that only a few counsellees thought that the counsellor *would prove to be* neutral and that only a few counsellees thought that the counsellor *should be neutral*. The difference in meaning is intentional and was understood by the counsellees themselves.

Dr. Winter claims that the postgraduate training of clinical geneticists includes extensive experience of counselling techniques. Consider, however, what Weatherall says in his monograph *The New Genetics and Clinical Practice* (London: Nuffield Provincial Hospitals Trust, 1983, p.125):

"We shall have to be very careful about our choice of counsellors in the future, and train them to present increasingly complex concepts in simple language. If communication with parents in genetic counselling clinics is anything like that throughout the rest of medical practice, I suspect that we have a long way to go in this critically important part of patient care".

With respect to Dr. Winter's claim that the relationship between counsellor and counsellee 'has nothing to do with whether the counsellor is medically qualified or not', I discussed the problem of doctors and counsellees confusing the two rules of informing and guiding in my last letter, and have nothing more to add to that.

Yours sincerely
Ivana Markova
Professor of Psychology
University of Stirling.

This correspondence is now closed.

WHAT IS THE AIDS PROBLEM?

Dr. Charles Forbes

Apart from the problem of dealing with patients who suffer from AIDS, perhaps one of the most difficult areas is to change the conception held by people of AIDS and its virus. This difficulty arises because if you take just the number of patients who present with AIDS, this will lead to a very significant underestimation of the prevalence of the infection. The infective agent is called Human T-cell Lymphotropic virus type III (HTLV III). It is now possible to identify people reliably that are infected with the virus, and this is done by detecting in their serum an antibody called anti-HTLV III.

I want to try and explain certain aspects about the virus and in particular make a contrast between the presence of the virus-infection within the community and the presence or the absence of virus related disease.

What is AIDS?

The Acquired Immuno Defiency Syndrome is a *syndrome.* This means that it is by definition a collection of clinical features or particular illnesses. In this particular context it is the result of long-term effects of infection with HTLV III.

Even if you accept that AIDS is caused by the virus HTLV III, it is still important to realise that there are many other features of infection by this virus. We now know that for every patient with AIDS there may be as many as one hundred additional people who have been infected with the virus, (who can be identified by detecting anti-HTLV III in their serum,) but who will have no evidence of illness as a result of the virus infection.

It is becoming increasingly clear however that a significant number of people may have other non-specific symptoms such as fever, diarrhoea and weight loss. These are all non-specific symptoms and occur commonly.

This then is a difficulty. However we think now that these illnesses occur more commonly in people who are HTLV III infected than in people who are not HTLV III infected. Also there is evidence that virus infected people who have these non-specific symptoms are more likely to develop severe immunological suppression than others.

The Americans have titled this group 'AIDS related complex (ARC)'. It is a very much less precise clinical definition nevertheless our experience indicates that it is of use.

For example, a doctor would take symptoms arising in the patient who is uninfected with the virus with a pinch of salt, on the other hand if a haemophiliac who is known to be seropositive for the virus (ie their serum contains anti-HTLV III) presents with a history of weight loss and fevers, it is important to exclude certain infections as a cause of the symptoms.

This realisation of varying degrees of illness caused by the virus has led to the concept of an 'iceberg'. By this I mean that if you look at an iceberg submerged in water the only part which is easily visible is the bit above the water. In this analogy, the part of HTLV III related disease which appears easily visible are those patients who have AIDS ie the tip of the iceberg. Beneath them are a much larger number of people who have mild ill health and beneath that group is the largest of all groups, people who are infected with the virus but who have no disease at all.

Who gets the disease

By all accounts, AIDS is a rare disease. In comparison to premature and unnecessary deaths from smoking, from cardiac disease and from road traffic accidents it pales into insignificance. However this does not mean that the disease or infection is in anyway insignificant for people who are infected with the virus and for those who know patients infected and affected by the virus.

There is always the danger of relating statistical data to individual people! If we examine the pattern of disease in the United States and this country we find that the major group who have the burden of disease are homosexual men.

In the United States the next major group is drug addicts. AIDS associated with blood and blood products in the United States is only a small proportion of the total number of ill people.

In the United Kingdom the prevalence of AIDS is slightly different, most cases have occured in homosexual men and drug addicts are poorly represented. The number of people in this country who have acquired AIDS as a result of blood or blood products, including haemophiliacs, is small but against that we know that in this country the proportion of haemophiliacs who have received commercial factor VIII that are sero positive is quite high.

At present in the United States there are more than ten thousand people with AIDS of whom about half have died. Most are homosexual men. The efficiency with which this virus spreads amongst gay men is remarkable. We see a similar situation in this country where the proportion of men who are infected attending gay clinics has increased from 2% in 1982 to 20% in 1984.

We do not know why the virus spreads so easily in this group but believe it is something to do with sexual activity. It maybe that anal intercourse is must more able to spread the virus than heterosexual vaginal intercourse. By contrast, transmission amongst drug addicts is to be expected, since we already know of a number of viruses which transmit as a result of sharing blood contaminated syringes and hypodermic needles.

Although the haemophiliac group is numerically the smallest both in the United Kingdom and in the US they represent particularly vexed problems. It is not through their sexual behaviour or lifestyle that they have become infected, rather it is the price of using pooled blood products. At this meeting I need not emphasise the requirement for pooled blood products. The use of pooled factor VIII has materially altered the lifestyle and life expectancy of the haemophiliac in this country.

However, the requirement for large doses of factor VIII has increased markedly the need for human plasma from which the factor VIII itself can be extracted. The result of this has been that people using commercial factor VIII will be exposed to blood products derived from panels of up to twenty thousand donors. Thus a rare infection occurring amongst those donors, even if only one or two maybe infected among the 20,000 can be expected to be transmitted to recipients of that pooled blood product.

In the case of HTLV III this is particularly likely, since people infected with the virus do not produce neutralizing antibody. By comparison other viruses may be neutralised by the mixing together of immune and non-immune sera in the plasma pool.

This enhancement of infection by the use of blood pools is what I have sometimes called a "Biological amplification" step. Paradoxically now the use of heat-treatment of factor VIII has removed the HTLV III risk from pooled blood products.

It is now the recipient of whole blood or cellular components of the blood who is the greatest risk of acquiring infection, simply because one cannot heat-treat red cells or white cells and still have a useful blood product.

The AIDS related virus (HTLV III)

You may have seen in the popular press mention of the phrase 'retro virus'. This refers to an unusual type of virus and there are a number of examples in humans, of which the AIDS virus is but one.

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WHAT IS THE AIDS PROBLEM?

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The family of human viruses are called Human T-cell Lymphotropic viruses (HTLV). Within this group are three members, types I, II and III, of which type III is associated with AIDS. It is called *Human* because it arises in humans, and *T-cell Lymphotropic* because it grows in the white blood cell which is called a T-cell. The credit for discovery of this virus is shared between the French and American workers, and priority of identification should probably go to the French group working in the Pasteur Institute headed by Dr Luc Montagnier.

What is a virus?

Germs which are quite common in the environment sometimes infect humans. When they do this they may cause disease; for example pimples, abcesses, pneumonia, meningitis and so on. Of the germs which infect humans, viruses are the smallest. As such, they do not "live" outside cells and are merely small pieces of information. They come, as most germs do, in many shapes and sizes.

Fortunately, the HTLV III virus has an outside layer which is very sensitive to damage, this is called the envelope. Inside it there is the central component which contains the "blue print" for other viruses copied from itself.

HTLV III is closely associated with cells but from the injection in haemophiliacs it clearly must be present in plasma. Thus, although lymphocytes (that is white cells) are probably the most dangerous components for infection, it can be passed in cell free serum and plasma.

In comparison with transfusion, prevention of transmission of living lymphocytes from person to person is quite easily achieved. They are very sensitive to detergent and heating. In everyday life they could only transmit through direct innoculation accidents, or perhaps through the close physical contact which occurs during sexual intercourse. General levels of hygiene such as hand washing and use of domestic bleach are expected to be very effective in preventing virus transmission.

For the virus to infect somebody it, or the cell containing it, needs to be in close contact with the patient's white cells. When this happens the white cell takes up the virus and the virus is then copied within that cell. That cell will then release further copies of the virus which will in turn infect adjacent cells.

There is an important step in this process which requires the use of an enzyme called 'reverse transcriptase'. It is from this enzyme that the virus family has required its name, *retroviruses*. This virus enzyme, reverse transcriptase, leads to the establishment of persistent infections in people who have been themselves exposed to and infected by the virus. It does this by taking the genetic information of the virus and putting it into the patients' chromosomes. This means that people who are infected by the virus probably become infected for life. This also unfortunately means that the person who is infected with the virus may also be infectious for life.

The origin of the virus remains uncertain. There is considerable speculation that it may have arisen from people infected in central Africa. There is evidence of a related virus in the Green Monkeys in the African continent, but it is unclear as to how or why this virus could have been transmitted from a monkey into a human. The general opinion is that the virus spread from America via Tahita to America, though the evidence for this is as yet unconvincing.

Transmission within Haemophiliac families

HTLV III infection transmits in blood and blood products and bisexual intercourse. The avoidance of accidental innoculation when attending a haemophiliac or when giving factor VIII injections is obviously of considerable importance. It has been shown in the past that hepatitis B will transmit within haemophiliac families by this route.

There is no evidence of HTLV III transmitting in the haemophiliac families in a similar manner but it is clearly necessary to take as many sensible precautions as possible to prevent the possibility of this happening.

In practice the single most important feature is to dispose of the used hypodermic needle which will be contaminated with blood in a manner so that no one else is likely to inoculate themselves on it.

Equally where somebody who is known to be virus infected has cut themselves and has bled, it is important that that blood and any objects contaminated with blood should be cleaned. This does not imply incineration or autoclaving, but merely wiping over with soapy detergent containing strong household domestic bleach.

The more vexed question is one of sexual transmission. There is evidence of a low level of transmission from haemophiliacs to their wives. It is not a common occurence and we can at present find no particular reason why it should have happened in any particular family.

It is our current belief that probably no more than one or two wives per hundred maybe infected with this virus. We have no way of knowing the outcome of that infection but would be concerned that they might transmit the infection onto their future children.

For this reason it seems appropriate that care should be taken when making love not to risk infection. In practice this means wearing a sheath. There is every reason to believe this would substantially reduce the risk of infection which is already fairly small.

Where transmission has occurred between husband and wife or boy and girlfriend, it seems important that this should be established since it would allow the couple to decide whether or not to have children.

The recommendation simply stated must be that a woman who is infected with the virus should plan not to have children at present. This will require careful and considerable counselling and adequate and comprehensive contraceptive advice.

The reasons for this are that the virus may transmit with ease from the mother to her unborn child, and there is increasing evidence that infected women during pregnancy suffer much more damage to their immune system from the virus. Both of these seem to be sound reasons for suggesting that the HTLV III infected women should at present not have children.

Future prospects

For all people infected with the virus, not only including haemophiliacs, two areas of concern remain. Firstly is to develop some way of preventing further people becoming infected. This is important not only in terms of public health in preventing the dissemination of this virus but is also important in the individual situations where the husband may be infected and the wife is as yet uninfected.

The future prospects for a vaccine are not good but I think one has to hope that in the years to come a vaccine will be developed. The second major area of concern is to modify the outcome of infection. This is particularly important when we consider that 25% of homosexual men attending clinics in London are already infected, and as high as 2/3 of recipients of commercial factor VIII may also be infected with this virus.

We cannot as yet say what the outcome of any particular infection will be, though we know, and as I have said earlier, certain features of disease may lead one to believe that a less favourable outcome is likely.

We would like to be able to have a blood test which would warn people when they are going to develop problems of immunosuppression. This is unavailable. It would also be tremendously useful to have some form of drug therapy in which one could modify the behaviour of the patient's immune system to the virus.

It would be particularly useful to have a virus suppressing drug, that is an anti viral agent which would suppress virus replication in the infected human. This might lead to a genuine cure for the virus infection. In addition to its use in the patient who is merely infected and who remains well, the patient who is beginning to develop signs of immunosuppression might benefit markedly from a virus suppressing drug.

Summary

HTLV III and the disease AIDS which it causes are not merely the province of gay men. The virus is quite able to transmit within humans and although it is essentially limited to certain risk groups urgent public health decisions need to be taken to prevent its further spread both in the risk groups and the gradual diffusion from those risk groups into the population as a whole.

Many people infected with the virus will probably remain entirely well throughout their lifetime. However there is an increasing number of people

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Clinical problems in AIDS care

Dr. Richard Tedder

Despite media coverage remaining high, public knowledge and facts about AIDS and related topics continues to be deficient or incorrect. The often hysterical, unbalanced and poorly researched articles in most newspapers has indeed produced a new syndrome, 'Fear of AIDS', a problem that is seriously stretching our already gravely overburdened counselling and diagnostic services.

The clinical problems that now face us fall into three rather distinct groups (a) the problems of patients with diagnosed AIDS (b) patients with AIDS—related complex (ARC) and (c) patients who have been found on screening to have a positive HTLV III antibody. In addition to the index patients in each group, we must see, advise and assist other family members, colleagues at work, school teachers, friends and lovers.

AIDS cases

While the total number of patients who have developed AIDS as a result of blood or blood product transfusion remains small there is little doubt that they have highlighted one of the most difficult and emotional facets of the much larger AIDS story.

To date approximately 28 European haemophiliacs (0.8 per 100) and 68 American haemophiliacs (3.8 per 1000) have contracted the disease from blood or blood products.

In addition cases of AIDS have now been reported from haemophiliacs in every country which has used imported American blood products. No cases of AIDS have been described in which only locally produced material (either cryoprecipitate or concentrate) has been used exclusively.

We now know however, that even local products may become contaminated with HTLV III virus and in at least two episodes in the U.K. seroconversion of haemophiliacs has occurred after local concentrate infusion.

The clinical features of AIDS have been well described previously in both the Bulletin and the AIDS fact sheet. There are no specific symptoms and because of this a clinical diagnosis is difficult to make early in the disease as some features resemble the other common self-limiting, viral infections.

Recurrent fever, weight loss, general malaise, diarrhoea, recurrent cough and swelling of the lymph nodes may be the presenting features and in a patient who has a positive HTLV III antibody will require further investigation.

A variety of opportunistic infections may also be found, these include herpes simplex (the virus of cold sores), candida albicans (a fungal agent which causes thrush), and Pneumocystic carinii (a protozoal agent which may cause pneumonia). A large number of other infectious agents have also been isolated and identified. Many of these are amenable to modern chemotherapeutic agents such as antibiotics and sulphonamides.

In addition there is an association of immune suppression with tumours of very special types and in unusual situations. Such tumours, of course, are treatable by standard forms of surgery but standard anti-tumour drug therapy presents a major problem as it also tends to further depress the marrow and exarcerbate the liability to infection.

In addition in some patients there is evidence that the virus may directly involve the brain cells and cause encephalitis with a disturbance in behaviour. This condition is well recognised with the other common viral infections.

AIDS—Related Complex

AIDS—related complex (ARC) has now been more accurately defined and is associated with lymphadenopahy in two different sites in the body, weight loss, fever, diarrhoea, fatigue; malaise and night sweats. These features are associated with defined immunological abnormalities and changes in the blood (a low platelet count, and a fall in the total white cells and lymphocytes).

There is growing evidence that these patients do not proceed to AIDS and eventually recover from their clinical problems although they continue to harbour the virus. Long term follow up and accurate charting of their problems will be required to evaluate their risk.

HTLV III antibody positivity

By far and away the most important group is the asymptomatic recipient of blood or the haemophiliac who is found on screening of his blood to have a positive antibody test to HTLV III virus. Recent international studies have shown significant differences in the incidence of such antibodies in various countries and between haemophilia A and B.

In large studies in the United States of patients with haemophilia A approximately half the patients have HTLV III antibodies but in some areas, several affected patient groups with a high consumption of factor VIII have up to 95 per cent of patients with a positive test.

In most of Europe the figures are much lower and range from 15-40 per cent for an equivalent group of severely affected patients. In America sero-conversion started in 1981-82 and continued in most of Europe soon after this date.

It is important to realise that the test only means that the person has been exposed to the virus and it is not meant that the person will progress to ARC or AIDS. Indeed in haemophilia it must be appreciated that there are significant differences from other "at risk" groups and figures obtained from homosexuals and i.v. drugs abusers do not necessarily apply.

So what is the significance of a positive test? In preliminary studies Dr.Gallo and his colleagues have isolated virus from the majority of antibody positive patients and in our current state of knowledge we must assume that such patients are potential carriers of the virus and possibly may infect others.

It is therefore reasonable to suggest simple precautions for every day life. These centre round the two important routes of transmission i.e. blood and semen. All blood spillage should be wiped up with a household disinfectant, all sharps should be returned to the Centres in appropriate containers for incineration, care must be taken when making up concentrates and relatives who assist should wear gloves.

To prevent sexual spread the use of a condom is to be recommended and advice about pregnancy sought. How-

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WHAT IS THE AIDS PROBLEM

who as a result of the infection develop severe immunosuppression. Once the immunosuppression has developed there is little that can be done to prevent severe disease.

The use of commercial factor VIII in particular, and pooled blood products in general has lead to a Biological amplification of this virus within the recipients. In this country as many as 2/3 of haemophiliacs who have received regular and large doses of commercial factor VIII may already have been infected with the virus. Steps need to be taken to prevent the spread of that infection from husbands to wives and boyfriends to girlfriends. In future one can see little risk attached to these of Factor VIII and other pooled blood products since the advent of pasturisation.

CLINICAL PROBLEMS

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ever it is important not to rely wholly on condom use for contraceptive purposes as in this change-over period we are aware of several pregnancies due to unfamiliarity with the technique. Full details of precautions to prevent HTLV III infection are to be found in the Society's literature.

It is of great importance to realise that a patient with a positive antibody test is not highly infectious as has been suggested by the media and indeed, in evidence from the U.S.A., no cases of AIDS transmission has occurred in health personnel who have been responsible for medical and nursing care or the handling of blood samples in laboratories. Reassurance should be actively given to other family members, friends, work mates and school teachers (see Table 1).

How can it be halted?

As blood has been the route by which the virus has been introduced into the haemophilic population the question arises how this can be halted.

Blood transfusion services are now aware of the risk of blood donations from "at-risk" groups and their sexual partners and now prohibit donation. Indeed in Scotland potential donors are warned in advance and are asked to sign a declaration that they have read and understood these requirements.

Unfortunately dishonesty or ignorance may render this method ineffective and it is probable that all donations in future will be tested. Such action will depend on development of an effective test and these are now coming onto the market from commercial sources.

The problem that this will highlight will be the asymptomatic donor who is found to have a positive test. A counselling service with long term medical supervision will require to be set up for this group.

A suggestion that women only should be donors has superficial attractions but would not be a practical possibility and would be ineffective as there is now heterosexual spread of infection.

Another suggestion is that for elective surgery the patients own cells (and plasma) could be collected and stored to be used later at the time of surgery. Such a scheme is probably impractical for the vast majority of the population and has major financial implications.

Risk of Transmission

The risk of transmission of the disease by individual units of blood from a screened population is minute. For pooled plasma concentrates from 5,000-15,000 donors the risk is greater. However HTLV III is heat sensitive and already heated Factor VIII and IX concentrates are available and an evaluation programme is underway.

Some Factor VIII is lost by the heating process—estimates vary from 20-40 per cent and this shortfall will require to be made up by more efficient plasma collection mechanisms from the community. Research is also continuing actively into genetically engineered Factor VIII and small test batches have been produced. Such a material would of course be free of HTLV III. It is only a matter of time before this becomes available—the best estimate being approximately five years.

As yet no antiviral agent has been known to be effective against this virus but current research work in this field is advancing rapidly. In addition with the molecular characterisation of the virus structure attempts are now pressing ahead rapidly to find a vaccine—but best estimates are that this will be a difficult task and many years away.

The initial hysteria about AIDS in haemophilia has started to abate and common sense prevails. There are many facets of the virus and the disease that we do not understand as yet and further intensive research is required. For the time being it is wise to carry out the sensible simple precautions to prevent spread of this infection.

Hopefully we will be able to stop the development of further cases with the production of heat treated products and gradually the irksome restrictions on life will be lifted.

Glossary of Terms

AIDS—acquired immunodeficiency which is characterised by the recurrence of opportunistic infections and tumours.

ARC—AIDS—related complex—a collection of symptoms and signs of disease including, lymphadenopathy, weight loss, fever, diarrohoea, fatigue, malaise and night sweats. A varient is PGL (persistent generalised lymphadenopathy) in which lymph-nodes are enlarged.

HTLV III—human T-cell lymphotropic virus III—is the same virus as LAV (Lymphadenopathy—associated virus). It is thought that this virus is the cause of AIDS/ARC. It acts by destroying the T-lymphocytes—cells responsible for the protection of the body against invading organisms.

HTLV III—antibody—is the body's response to infection with HTLV III and is used as a marker of exposure to the virus. It is not an antibody which kills the virus. There is evidence that the virus can still continue to live in the lymphocytes of patients who have this antibody. Seroconversion is when the blood tests for the antibody becomes positive.

Opportunistic infection—is infection by low grade organisms which is normal people are instantly removed by the immune system. Often these organisms live normally in our body and are kept in check. However when immunity is depressed they invade the tissues to produce disease.

Herpes simplex—is a virus infection which is commonly seen as the cause of cold sores.

Candida albicans—is a fungal infection which is commonly found in the skin, in the mouth and in the vagina of healthy persons. It may occasionally spread even in fit people to produce inflammation e.g. 'thrush'.

Pneumocystis carinii—is a protozoal organism which may cause pneumonia in immunosuppressed patients.

Encephalitis—an inflammation of the brain cells which results from a virus infection.

Lymphadenopathy—enlargement of the lymph nodes which are the organs into which the lymph drains and often are the first site of defence against invading organisms.

Recommendations for the individual HTLV III antibody positive

1) Regular medical follow up
2) Refrain from donating blood, plasma, organs or sperm.
3) Risk of infection—sex, intimate contact, needles.
4) Avoid sharing implements which may be blood contaminated—razor, toothbrush.
5) Clean any blood or concentrate spillage with household bleach.
6) Safe disposal of "sharps".
7) Delay pregnancy.
8) Inform any other paramedical personnel i.e. dentist, chiropodist.

The two papers reproduced from pages 3 – 6 were originally given by Dr. Charles Forbes and Dr. Richard Tedder at the AGM.

Dr. Forbes is the Director of Glasgow Haemophilia Centre, and Dr. Tedder is senior lecturer and consultant virologist at the Middlesex Hospital.

FUNDS RAISED IN N.IRELAND

Our friends in Northern Ireland may feel a little out of the mainstream of Society affairs, but their fund raising efforts have been tremendous. Just look at this list.

£279 from a dance run by Pearce Ogg Social & Development Club, Armagh. Cheque presented by Madelene and Pete Donnelly.

£424 from a tournament run by Holywood Gold Club. Cheque received by Bill Johnstone.

£210 from a dance organised by Mr. & Mrs. B. Donnelly.

£925 from Northern Ireland Darts Association, from their Charity Cup finals in Portadown. (Cheque received by Seamus McGarth).

FLAG DAYS

Flag Days have produced: Armagh £281 (Mrs. Madelene Donnelly and friends); Bangor £379 (Bill Johnstone and friends); Belfast £762 (Seamus McGrath and friends); Dungannon £414 (Mrs. Madelene Donnelly and friends); Glengormley £91 (Mrs. Valerie Cassells and friends).

£50 donation from Gallaher's Charity Fund; £111 donation from the Ulster Museum, Belfast; £100 donation from the "East Belfast Women Together" movement, and £500 donated by the Belfast & District Darts League.

This team of Prison Officers from Parkhurst Prison, along with representatives from the Parachute Regiment recently organised a sponsored assault course event—benefitting the Society by £250. Well done and thank you!

MONEY FROM THIS-and-THAT

North Eastern group have been hard at it raising funds from all sorts of do's. Collecting boxes at the Arndale Centre in Bradford netted £93, and they did well at another in Leeds a few weeks later.

A Leeds jumble sale produced over £100, and when we went to press they were about to run a stall in the John Street Market, Bradford.

UNDER-WATER SWIM RAISED FUNDS

A one-hour non-stop underwater swim raised £300 for the Society in June.

Members of Ashfield Sub Aqua Club undertook the swim and swam non-stop for 50 lengths of the public baths at Sutton.

The cheque was presented to Sheffield group member Geoff Flavell, who thanked all those involved.

LITERATURE FROM STOCK

Just a reminder to members that copies of our new book **"Introduction to Haemophilia"** are available free of charge from Head Office. This publication replaces all the former "Notes for . . . " series, except **"Notes for Parents"** which remains in print. The new "Introduction to Haemophilia" is especially suitable for teachers and careers advisers.

Also available from Head Office is the Heamofact Special Edition—**"Advice on Safer Sex"**. This publication, which will be of particular interest to members who are HTLV III antibody positive is available free of charge. Write or telephone for your free copy.

Books by Dr. Peter Jones are still available too. They include: **"Living With Haemophilia'**, 2nd edition. £9.49 inc. P & P to Society members; **"Aids and the Blood"**, £.50 plus 50p P & P.; **"Haemophilia Home Therapy"**, £8 per copy, including P & P.

WHAT CAN THE SOCIETY DO FOR YOU!

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

- Making representations to the Government
- Securing high standards of treatment
- Making publications available to members, doctors, nurses, social workers, physiotherapists and other health care professionals
- Providing help to people with haemophilia
- Limited support to vital research projects

More especially the Society can help you by:-

Keeping you up to date on developments in treatment and care through our literature—this applies especially to AIDS

Answering any questions you have

Assisting you to obtain Mobility Allowance for your children

Advising on special travel arrangements, treatment centres abroad and in the UK, Documentation, travel insurance, etc.

Society caravans for UK holidays

Arranging exchange travel and summer camps with special facilities for teenagers with haemophilia

A BRIGHTON RUN—BY BIKE

We see from the Lewisham group's newsletter that 'the energetic family Robinson' have planned a sponsored bike ride for next Spring, from Bromley to Brighton.

They seek offers of riders, spare bikes, sponsors or any other offers. Ring Barbara on GRO-C if you can help.

SPECIAL AWARDS FOR PEOPLE WITH HAEMOPHILLIA

Each year, through the generosity of Catharine Cookson and Brendan Foster we are able to offer two prizes (one junior and one senior) for outstanding achievement in sport and for achievement in education.

Nominations are invited both junior and senior awards as follows:—

The Catharine Cookson Awards:

These awards (one senior and one junior) will be given for academic achievement. This need not necessarily depend on success in competitive examinations, especially in the younger age group.

In addition to the general details requested, each entry should include the names and addresses of two referees, one a doctor with personal knowledge of the candidate's disorder and its severity, and the other a school teacher or lecturer with personal knowledge of the candidate's academic achievement.

Brendan Foster Awards:

These awards (one senior and one junior) will be given for achievement in any field sport (indoor or outdoor). Each entry should include the names and addresses of two referees, one a doctor with personal knowledge of the candidate's disorder and its severity, and the other a sports teacher or coach with personal knowledge of the candidate's achievement in his or her chosen sport.

General: There will be two senior and two junior awards. Each senior award wil be in the form of a personal certificate and a cheque for £25.

Senior awards will be open to those over the age of 12 years and, usually, below the age of 21 years.

Junior awards will be open to all children with haemophilia or another disorder of haemostasis below the age of 12 years.

Award winners will be selected annually. The judges will be Mrs. Cookson, Mr. Foster, the Chairman of the Haemophilia Society and the Director of the Newcastle Haemophilia Centre.

All entries and references will remain confidential to the judges, and no names or other details of any entry will be divulged without the written permission of the candidate and/or his or her parents or guardian.

In deciding the winner of each award the judges will take into account the candidate's haemophilic disorder and its severity.

Competition for awards is limited to the United Kingdom. The decision of the judging panel will be final.

Entries for the awards should be sent to the National Haemophilia Awards for Achievement, Newcastle Haemophilia Centre, Royal Victoria Infirmary, Newcastle upon Tyne, NE1 4LP, marking envelopes 'AWARDS'.

All entries received will be acknowledged. The closing date for entries in any one year is September 30.

ANNUAL DRAW A GREAT SUCCESS

The 1985 Annual Draw was another show-stopper – an all-time record-breaking income of £13,000 – plus a little bit more!! All the prizes were donated by companies throughout the UK; so our only cost was for printing the tickets.

By now you should have received a copy of the prize-winners list. If not, just ask and we will let you have one.

Well done everyone who sold or bought tickets – get ready for 1986 when we hope to have even bigger and better prizes.

Meanwhile, we are grateful to the Northern Group for organising a social evening for the draw.

COLCHESTER WIN A CUP

Colchester group entered a float in their local carnival procession in July . . . and won first prize in their section.

The 'Cup' carried with it a prize of £5, and the Carnival committee have promised a donation to the Society.

HE MUST HAVE WEBBED FEET

We hear of a quite remarkable achievement from Colchester group. Committee member Mrs. C. Evans' son Robert, a 14-year-old haemophiliac, raised over £40 for the Society when he took part in a sponsored swim at Sudbury baths.

Robert swam the equivalent of 11.1/2 miles!

Dr. D. I. K. Evans, consultant haematologist at Alder Hey gets ready to send off the competitors in the annual cycle race organised by North West group.

North West's group held a raffle at Adlington during the summer and in our picture group chairman Norma Guy is pictured with vice-chairman Norman Johnston presenting Susan Gaul with the colour tv top prize.

WELL DONE BOYS

You could hardly call Lee Hepworth (9), Sean Briggs (10) or Kenneth Driver (8) 'tiny tots', but they certainly ran their little hearts out for the Haemophilia Society.

The three boys all come from the Flanshaw Estate at Lupset, Bradford, and ran six miles to raise £27.17.

Said Myrna Walker, chairman of the North Eastern group: "It shows that kids today aren't all bad."

1986 RESIDENTIAL SEMINAR

Places are available at the 1986 Seminar for Society members who wish to attend. The Seminar will be held over the weekend February 28 - March 2 1986. Cost for the weekend **FULL BOARD** from Friday dinner to Sunday Lunch is £55, including accommodation in the Seminar Hotel - The Heathlands, Bournemouth.

You will have an absorbing and interesting weekend with interesting workshops, lectures, time to relax and share experience with people with haemophilia, wives, sisters, etc . . . a worthwhile break!

Financial assistance may be available in a limited number of cases where members wish to attend but cannot afford the full cost.

Please write immediately to the Co-ordinator for full details of the weekend and a booking form.