Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

**INFECTED BLOOD INQUIRY**

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**WITN6392200**

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1990 No. 3

# The Bulletin

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

Member of the World Federation of Hemophilia
Registered Charity number: 288260

**The Haemophilia Society**
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# ON THE COMPENSATION TRAIL

## Background on our campaign

**Over the last few weeks there has been more than usual coverage in the national media about haemophilia and the campaign for justice for people with haemophilia and HIV infection.**

**Some of the stories and items are generated by the Society as part of our campaign. Some reflect the efforts of politicians on our behalf. Others stem from the concern than many journalists feel that there is an issue of public interest at stake.**

**There are now several different parts to this campaign and this article may help to clarify the current position.**

## *Court Cases*

The fear which we have often voiced about the length of time it might take to pursue legal actions is as real as ever. Late in July a "trial within a trial" took place to establish whether the government could be required to produce the papers which our claimants' lawyers need. As we go to press we do not know the outcome of this hearing, but whatever the judge's decision may be, an appeal is likely, with inevitable further delays.

## *Parliamentary action*

Fearing that the government might try to refuse to co-operate in the production of papers in court, Audrey Wise MP tabled an Early Day Motion in the Commons calling on the government not to attempt to hide behind public interest immunity. This motion attracted 90 signatures from MPs of all parties within hours of being introduced. We would encourage you to ask your MP to sign this motion **(EDM No 1334 HELP FOR PEOPLE WITH HAEMOPHILIA AND HIV)** before the start of the next parliamentary session in October.

## *Ombudsman*

In the last Update we reported that Alf Morris MP had asked for an inquiry to be conducted by the recently retired Ombudsman into the general issue of compensation, and that this request had been turned down by the Prime Minister.

Since then Mr Morris has been asked to take a case to the current Ombudsman, William Reid, alleging maladministration on the part of the government. This action would benefit those who have not yet started a legal action through the courts. Members who are in that situation, whether for financial or any other reasons, should write urgently to The Rt Hon Alfred Morris MP. If you would like more information about this course of action please write to the General Secretary who can supply you with fuller written details. It is hoped that the Ombudsman may be able to investigate the matter and reach a solution more speedily than appears likely through the Courts.

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## *National media*

As you will appreciate, co-ordinating all these activities and supplying our members and their representatives with information and advice places great demands on our limited resources. When additional stories, like the moving "Mail on Sunday" feature on our members GRO-D and GRO-D or programmes such as "The Cook Report" or "Dispatches", arise we have to make difficult and speedy decisions as to whether to respond and enter into public debates on the issues they raise. Often our decision has to be that we do not have sufficient time to follow up every mention of haemophilia in the media. We are sure that members will understand that this does not reflect any lack of interest in these affairs, but rather a measured decision to apply ourselves to our campaign to achieve a just settlement of a cause which is so important to so many of our families.

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# Travelling to the USA and the World Federation of Hemophilia Congress

The Executive Committee have voted unanimously to continue to boycott all travel to the USA which uses Society resources in view of the on-going immigration policy which denies free entry to those who are HIV antibody positive. The text of our formal communique on the subject sets out our detailed reasons for maintaining our original position. We would only add that the decision process has not been easy and that the Executive Committee deeply regret their inability to support the Congress by their attendance. We salute what has been achieved but feel that the US government has shown an unwillingness to respond sensitively to a very real issue in which they could lead the rest of the world positively. The General Secretary wrote as follows to Charles Carman, President of the WFH on May 22 1990:—

Dear Charles
I am writing to thank you for your letter of 3 May 1990 and, at the request of the UK Executive Committee, to let you know the outcome of their deliberations at their meeting in London last night. The discussion was long and careful and all present recognised and welcomed what had been achieved by the staff and volunteers of both the World Federation of Hemophilia and the National Hemophilia Foundation. There was praise for the energy and commitment shown by those organisations to the cause. The Executive Committee was happy with what had been achieved to date by the boycott of all travel to the USA and they appreciated the understanding shown by WFH regarding the value of that boycott in achieving the current position.

However, following their lengthy and painful consideration of the matter, it was unanimously resolved that the UK position would remain unchanged. The Committee did not feel able to accept a short-term privilege which would apply *only* to attendance at the Congress but which would not apply to the ordinary family with haemophilia either before or after this window period. In addition, while the Committee noted the assurances about travel and the facility for travelling without a special visa, the US Embassy in London is adamant that to do so would place one in jeopardy. The only safe and correct procedure is to apply for the special ten day visa.

The Committee have also asked me to emphasise that the boycott was *primarily* against all travel to the USA for whatever purpose: the fact that our Congress was to be held in Washington involved a secondary – and highly regrettable – factor. You will recall from our earlier communications that we were anxious, for that reason, for the Congress be moved out of the USA.

The Committee had also understood that President Bush retained the authority to suspend the legislation pending a review and not for short periods of time only. A suspension for a period such as would have enabled the legislation to be reviewed could have had a greater impact on the Committee in reaching an alternative decision.

I must also let you know how much the UK Society agonised over this decision and how much they regret not being able to participate in the forthcoming Congress. Apart from the original decision to implement a boycott, I have known no other discussion to have caused so much very real pain and anguish to our Committee members. They have especially asked that I re-endorse their total commitment to the principles of the Federation – our 1990 subscription is on its way!

We will continue to use our best endeavours, even from this distance, to persuade your authorities to change their position. You must let us know of any further actions we can take to secure that change.
Yours sincerely
David Watters
General Secretary
May 11 1990.

# THE SOCIETY AND CAMPAIGNING

**We reproduce the text of a speech by Rory Chisholm of GJW Government Relations Ltd, delivered at the 1990 annual general meeting following presentation of the 1990 Haemophilia Society Award.**

**Rory, and Steven Jackson, also from GJW, have worked with the Society on campaigning issues for almost a year and our Award represents our gratitude to them both and to GJW.**

GJW Government Relations have been working closely with the Chairman and General Secretary of the Society since September last year. I would hope that it has proved a rewarding experience for both our organisations. For me personally, it has been one of the most interesting and challenging campaigns I have been associated with since I started working in the area of government relations some years ago. I would like to say a few words about where we stand now on the all-important question of compensation.

The government has at no stage admitted legal liability for the infection of many of the Society's members through the use of infected blood products on the National Health Service. Briefly, their position is that those who were infected were the victims of a medical accident, but not actual negligence. Under the present law, there is no automatic compensation for victims of medical accidents. Instead, negligence must be proven if liability is to be established. As you know, this is the position which many of you are currently challenging in the courts.

My role is to assist the Haemophilia Society in persuading the government that a form of no-fault compensation should be agreed in an out-of-court settlement. This is not because we think that those taking legal action will be unsuccessful. It is because by the time the legal action is resolved, many of those infected with HIV may no longer be with us. Legal compensation will be too late. Therefore, we have tried to persuade the government to provide a realistic level of compensation as soon as possible.

To some extent we have been successful. Last November the government announced that a series of ex-gratia payments amounting to £20,000 per person would be paid to each person with haemophilia and HIV. This was largely the result of, firstly, considerable lobbying of Members of Parliament and, secondly, extensive and sympathetic coverage in the media. It would not have been possible to secure these payments without the support of both groups. However, the support of both the House of Commons and the media depended, in turn, upon the courage of many members of the Society in going to see their constituency MP and in being willing to be interviewed by the media. Without this, the efforts which the Society and my own organisation have made on the membership's behalf would have been much more difficult. I would like now to record my thanks to those people.

*Rory Chisholm receives the 1990 Haemophilia Society Award from our chairman the Revd. Alan Tanner.*

However, the question of proper compensation has still not been fully resolved. There are three main reasons for this. Firstly, the Department of Health, like all other government departments, does not like to spend even small amounts of public money on areas for which it has not budgeted in advance. Secondly, the Department of Health is not yet persuaded that there is sufficient public and parliamentary concern to oblige it to provide a decent level of compensation to all those with haemophilia and HIV. Thirdly, even if the Department of Health can be persuaded to ask the Treasury to provide sufficient funds to allow a decent level of compensation to be paid, it is likely to be extremely difficult to get the Treasury to agree due to the government's fear of setting a legal precedent for others who have suffered as a result of medical misjudgement.

What can be done to overcome each of these obstacles? Well, as before our main weapon remains the concern of both public and parliamentary opinion. Since November, the Society and my own organisation have worked hard to ensure that Members of Parliament are aware of our continuing concerns with regard to compensation and sympathetic to our arguments. We are continuing this lobbying process and are constantly looking at ways of involving Parliament further.

Much has also been done to keep up good links with the media, as well as with the government itself. But as before, these efforts are only part of the process of winning sufficient public and parliamentary opinion to our side. Unless we have the continuing and active support of members of the Society who are prepared to argue our case, in public if need be, then the efforts which we are making will be greatly undermined. We are currently looking at ways in which the membership can be more actively involved, at both a local level as well as nationally, while aiming to preserve anonymity for those for whom it is absolutely essential. I hope you will respond when the call comes.

In most of the lobbying campaigns in which I have been involved, timing has been everything. On this issue, we do not have that option. Time is our great enemy, and we all wish to see the issue of full compensation resolved as soon as possible. However, there are certain constraints. As I have made clear, the support of parliament has been and will continue to be essential. Unfortunately, parliament does not sit all year, and there is an especially long recess during the summer and early autumn. There is obviously no point in trying to raise an issue as a matter of urgency with an MP when he or she is away. So in all our work, patience is required as well as perseverance and persuasion.

In the end I am confident that our efforts will not be in vain. Although I have sought to emphasise that there are many difficulties which lie ahead, I remain optimistic that most people who understand how and why this situation arose are willing to take our part. This is an emotive issue. We must not allow it to fade away, nor to cloud our judgement. Nor must we lose heart in the months ahead. The government has responded positively so far because it felt it had no option but to be seen to be doing something. Now we must persuade it to do more. Some people will accuse us of being greedy. Remind them of the level of compensation for others who have suffered personal and physical tragedy in the Clapham rail crash, the Lockerbie disaster, and a host of other lesser known tragedies. We are not greedy but fair.

Your General Secretary has described the situation as the greatest single disaster in the history of the NHS. We will not let it disappear from view. The Society can tell you to whom to address your concerns and when to do so. The rest is up to you. It is a long and hard struggle that faces us, but ways can and must be found to get the government to face up to its responsibilities.

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## ARMOURPAGE

My husband and I would like to thank the Society for setting up the 'Armourpage'. Our grateful thanks go to Armour Pharmaceuticals and British Telecom for sponsoring such a worthwhile service.

We are now into the third week of using the pager, and I can't tell you how reassuring it is to know that within a matter of minutes we can be contacted if need be.

Our son, is now 21 months old and you can guess – into everything. We feel so much more confident when we have time out together, and family are certainly a lot happier to look after him for longer periods.

Thank you again, and for your support through the 'Bulletin' and Update.

Yours sincerely

GRO-D

Editor: We are receiving a large number of letters expressing these sentiments.

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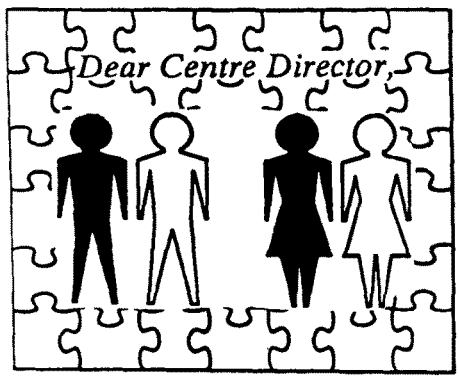
**Dear Director**

*"One area I would like information on is the whole question of alternative therapies in the treatment of HIV/AIDS in people with haemophilia. In books mainly aimed at gay men there are suggestions that things like visualisation, lymph massage, homeopathic remedies, vitamin supplements, etc. etc, are helpful in inhibiting the progression of HIV/AIDS. Do they apply to people with haemophilia?*

**A. Patient**




## "ANY PORT IN A STORM" "LOOK BEFORE YOU LEAP"

Many traditional sayings of this kind can be found to express opposite points of view. In this case they can be used to illustrate the natural desire to find a solution to the AIDS problem at any cost – or to be cautious and use the scientific knowledge we have to improve the quality of life without doing more harm. This dilemma is as old as medicine itself.

People with haemophilia have had every reason to believe in modern medicine. Few older patients with severe haemophilia would dispute that their lives have been transformed since 1965 when cryoprecipitate was introduced. Scientific principles could at last be applied to their painful illness on a large scale and real progress has since been made, leading to all the benefits that home treatment, prophylaxis, surgery, genetic counselling, antenatal diagnosis and even synthetic factor VIII concentrate have to offer.

The century began very differently. The Royal haemophilia in the descendants of Queen Victoria brought into sharp focus the terrible experiences of those less privileged members of the population who lived and died unnoticed. The fate of the Russian Royal Family also showed the dangerous effect and real power that can be brought to bear by a charismatic but unprincipled individual when introduced to a vulnerable family in distress. Rasputin's influence over the Tsarina seems to have been both frightening and destructive and some historians have suggested that it may even have played a small part in the Russian Revolution itself.

The worse the situation the more desperate we feel. AIDS confronts the human race with the greatest medical challenge of our times and the haemophilia community has tragically been at the forefront of the epidemic. I suspect that everyone has some minor superstition or irrational belief and who can be blamed for feeling that there must be *something* they can do to help themselves? It is in this context that comparatively simple measures such as homeopathy, vitamin supplements and special diets look very attractive, even though there is no scientific proof that they work. Neither do we know the *real* importance of factor VIII in stimulating or suppressing the immune mechanism of people with haemophilia. We do know that people with haemophilia and HIV infection seem to have a prospect at least as good as those in other groups but otherwise we can only speculate until hard scientific information becomes available.

**WHAT THEN ARE WE TO DO?**

Despite all the difficulties I believe that haemophilia doctors and people with haemophilia will do best to face their problems together. It is my experience that there *is* still confidence in the relationship and that we are learning valuable lessons in the fight against haemophilia and AIDS. I would therefore advise patients to continue to put their trust in their haemophilia centre (and in the Haemophilia Society). If you are attracted to alternative therapies discuss them with your Centre Director and see whether or not you can combine them with the more conventional approach your centre offers. Talk to the Society and to the members of your groups and try to give *each other* the help you need so much. It may be that this mutual support will be worth a hundred alternative therapies. Finally be cautious before leaving the tried and tested path. Sadly there are many pitfalls awaiting those who put their faith in the untrustworthy and none of us is at our best when making judgements of this kind in a crisis.

Better the treatment you know!

## At last the UK Centre Directory

It is many years since a new UK Centre Directory was produced and even that document was not particularly useful since it was merely a list of, now outdated, names and addresses. The new publication will be **the definitive work!** It will list a great deal of useful information about each Centre and the plan is to update the booklet regularly.

The fact that BPL – which now stands for **Bio Products Laboratory** – is a fully fledged commercial operation has meant that they are now in a position to sponsor the publication. We welcome this new initiative and co-operation and look forward to being able to supply all members with a copy later in the year. They will be mailed automatically as well as being available through Centres.

**NR**

# Psychological and social impact of HIV infection in men with haemophilia

by Dr Jose Catalan, Senior Lecturer in Liaison Psychiatry, Charing Cross and Westminster Medical School, London and Mrs Ivana Klimes, Principal Clinical Psychologist, Department of Psychology, Warneford Hospital, Oxford.

For nearly four years we have been involved in research into the psychosocial impact of HIV infection on men with haemophilia and their partners, and for the last two years we have also been studying and monitoring the possible effects of HIV infection on brain functioning.

It is important to study HIV infection in persons with haemophilia, not only for the purposes of clarifying the problems and special needs they have, but also to be able to gain a better understanding of HIV disease in general: it cannot be assumed that the virus will behave in exactly the same way in different people, and so a more accurate picture of the disease will be obtained if different populations and individuals are studied in detail.

The research projects have been funded by the Oxford Regional Health Authority and the Wellcome Trust and the work has been carried out at the Oxford Haemophilia Centre, in collaboration with Dr Charles Rizza, its Director. Our research team includes Alison Bond, Adrianne Garrod, Ann Day and Selena Elcombe.

The research would not have been possible without the commitment and enthusiasm of many men with haemophilia and their partners who have volunteered to be involved in this research, and who have spent many hours talking to members of our research team about many aspects of their lives. We are very grateful to them for their collaboration and suggestions.

## THE FIRST STUDY

Our first study measured the impact of living with HIV infection. We compared men with HIV infection who were asymptomatic, and a group of sero-negative men with haemophilia. We also interviewed their partners. Most of the people in our study had known their HIV status for at least three years, and so we were not able to study the immediate impact of notification of HIV status, but rather the medium-term consequences.

We found that HIV positive men were more likely to experience symptoms of psychological distress, such as depression or anxiety, and also to have greater feelings of hopelessness about the future than sero-negative men. HIV infection had also had an adverse impact on their sex lives, and many HIV sero-positive men described sexual problems, including difficulties with erection and ejaculation. Condom use was found to be fairly consistent in sero-negative men, but many reported fear of transmitting the infection to their partners, in spite of the precautions taken.

The wives and partners of men with haemophilia had generally worse levels of psychological distress than the men, but this was regardless of the HIV status of their husbands. These findings should not be taken to mean that HIV infection does not cause problems to the partners, but rather that being married to a man with haemophilia, even if he is HIV sero-negative, can still be a source of considerable stress.

In the last 18 months we have begun a five-year study which involves six-monthly interviews with sero-positive and sero-negative men. In this study, in addition to assessing the psychosocial and sexual effects of infection over time, very much along similar lines to the earlier project, we are also looking in detail at brain functioning, in particular such things as memory, attention, concentration, reasoning power etc. The reason for being concerned with assessing these functions is the possibility of HIV infection affecting the nervous system.

Our preliminary results from this follow up study are reassuring. HIV sero-positive men with haemophilia who are well perform as well on neuropsychological tests as sero-negative men with haemophilia. This suggests that HIV infection is unlikely to affect the central nervous system in sero-positives who remain well. Our findings are consistent with those of other investigators in this country and in the USA who have studied HIV sero-positive individuals belonging to other transmission groups (gay and bisexual men and drug users). Preliminary results from the psychosocial arm of this follow-up study also offers some reassurance – while our earlier study found that sero-positive men had greater levels of psychological distress than sero-negatives, more recent findings suggest that there is little difference between sero-positive men with haemophilia who remain asymptomatic and their sero-negative counterparts. However, sero-positives still report greater adverse impact of HIV infection on their sex lives, and their family life is under greater strain.

The studies briefly described here highlight some of the effects HIV infection has had on men with haemophilia and their partners so far. They suggest possible areas for further psychological support and advice both for the men with the infection and their partners, but also for those who, while remaining sero-negative, may still be experiencing problems, and this particularly refers to the wives and partners of men with haemophilia. Our research will continue for another three years, and we thank in advance the help and effort given by the volunteers involved in the study, and also that given by staff at the Oxford Haemophilia Centre.

NR

# WOMEN AND AIDS: CURRENT KNOWLEDGE

The Haemophilia Society would like to thank AIDS ACTION (December 1989, Issue 9) for permission to reproduce thia article.

## TRANSMISSION OF HIV INFECTION FROM MOTHER TO CHILD

**Transmission of HIV (the virus that causes AIDS) from an infected mother to her foetus (unborn child) or infant is thought to occur in 20-40 per cent of cases. Data collected so far suggests that women who have symptoms of HIV-related disease/AIDS are more likely to transmit the virus to their child (before, or during, birth) than women who have asymptomatic infection (that is, they have the virus but do not show signs of illness).**

**Asymptomatic infection can last eight or more years. It is also possible that women at the stage just after being infected (for example, during the first few days or weeks), are more infectious than at the later stage of asymptomatic infection. This means that if a woman is pregnant, or breastfeeding, at the time of infection with HIV (for example, through a blood transfusion), there may be a higher chance of HIV transmission to her foetus or infant.**

### Transmission before birth (prepartum)

HIV transmission, via the placenta, can occur even in the first three months of pregnancy. In studies, HIV has been found in foetuses aborted within the first three months. There is evidence that women who have AIDS have a higher than average rate of spontaneous abortion.

### Transmission during birth (intrapartum)

Transmission of HIV from an infected mother to her infant can occur during birth, probably because the infant is exposed to a large amount of HIV infected maternal blood and secretions during delivery. Nevertheless, studies comparing the rate of perinatal HIV transmission appear to show no difference in transmission according to the mode of delivery, that is, whether the infant is delivered vaginally or by caesarian section.

### Transmission after birth (postnatal)

Handling and cuddling of her baby by a mother with HIV infection does not transmit HIV to the baby. The risk of transmission via breastmilk is apparently very low. Risk of infection via breastmilk is probably greatest if the mother is infected after birth, and sero-converts (becomes HIV antibody positive) while breastfeeding.

The immunological, nutritional, psychosocial and child spacing benefits of breastfeeding are well recognised. Breastmilk is also important in preventing infections which could accelerate the progression of HIV-related disease in already infected infants. In situations where the mother is considered to be HIV-infected, and recognising the difficulties in assessing the infection status of the newborn, the known benefits of breastfeeding should be compared to the theoretical, but apparently small risk to the infant of becoming infected through breastfeeding. In many circumstances, and particularly where the safe use of alternatives is not possible, breastfeeding by the mother should continue, irrespective of her HIV infection status.

*Other routes of transmission to infants and children include:*

- Infected blood transfusions. In areas where blood is not screened for HIV, blood transfusions have been shown to be an important route of HIV transmission to children.
- Improperly sterilised needles and syringes have been associated with transmission of HIV infection to children. See *Guidelines on Sterilisation and Disinfection Methods Effective against HIV* (WHO AIDS Series No. 2, 2nd Ed., 1989).

*Other potential risk factors for HIV transmission to children include:*

- Sexual abuse of infants/ children by an infected adult.
- Ritual scarification or other traditional practices which involve cutting the skin with equipment not properly sterilised between each use.

**A child cannot get HIV infection from ordinary physical contact, such as playing and hugging, with an HIV-infected mother or other family member. HIV is not transmitted by insects, such as bedbugs or mosquitoes; or from sharing or using things in the same house, including using the same lavatory or pit latrine.**

## PAEDIATRIC HIV INFECTION/ AIDS

### Testing for HIV infection

Testing for HIV antibodies in the blood of an infant under 12-18 months of age does not provide a definitive diagnosis of HIV infection/AIDS in the infant. This is because the mother's HIV antibodies (if she is infected) may remain in the baby's blood for up to 18 months. The antibody test, therefore, will as likely reveal antibodies from the mother as from the child.

If the child is under 18 months old, HIV infection cannot be proven in the majority of cases in the absence of a diagnosis of AIDS. After 18 months, the presence of antibodies to HIV in an infant indicates the presence of HIV infection. An unknown percentage of infants of HIV seropositive mothers die of unconfirmed HIV infection before reaching 18 months of age.

A few children who are HIV seropositive at birth (due to the presence of their mother's antibodies) subsequently test negative for HIV antibodies **but** have clinical symptoms which indicate HIV disease/ AIDS and are found to be HIV-infected. This means that children who are HIV antibody positive at birth should have long-term follow up even if they test antibody negative after 18 months; there is a very small chance that they could still be HIV infected and develop AIDS.

### Definitions and clinical manifestations

The Centres for Disease Control case definition for AIDS was established mainly for reporting purposes in developed countries and is less useful in developing countries where laboratory facilities are limited.

The proposed WHO clinical case definition of AIDS in infants and children (see *Weekly Epidemiological Record*, 1986, Volume 61, pp. 69-76) lists a number of clinical symptoms. However, in developing countries, the clinical manifestations of HIV-related disease and AIDS are frequently difficult to distinguish from the clinical manifestations of other severe and common illnesses of childhood. The most common opportunistic infections in HIV-infected children are *pneumocystis carinii* pneumonia (PCP) and *candida oesophagitis*, although bacterial infections are also a common finding. PCP tends to occur in the young infant. Lymphoid interstitial pneumonia (LIP) usually occurs at two to three years of age. Neurological manifestations may appear early.

*(Continued on following page)*

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# HIV AND PREGNANCY

## What every mother-to-be should know

All women who are pregnant, or who wish to have children in the future, should be informed about HIV infection/AIDS. They should be told how the virus is, and is not, transmitted, and encouraged to consider whether they think they could be infected, or at risk of infection. Pregnant women should be told the following facts:

- if the mother is infected, there is a chance (between 20 and 40 per cent) that her unborn baby may be infected
- the risk of transmission is probably highest if the mother becomes infected with HIV during pregnancy, or is already showing signs of AIDS
- an infected infant may die within the first few years of life.

## Testing pregnant women

Where mothers are to be confidentially tested for HIV, they must all be counselled, so that they fully understand the implications of HIV testing. Testing should be voluntary and confidential.

Some women, and their health workers, may find that there is good reason to suspect HIV infection. Under these circumstances a pregnant woman may also choose to have a test, since this could affect her decision about continuing the pregnancy.

Conclusive studies of the influence of pregnancy on progression of HIV disease in women have not yet been completed. There is at present no firm evidence to suggest that pregnancy adversely affects the health of an HIV-infected woman.

HIV antibody testing of a newborn infant only reliably indicates the HIV infection status of the mother and not the infant. Antibody testing of a newborn infant that is linked to identifying information should only be done where it is clearly indicated for the clinical care of the child. Testing infants raises the problem of possible discrimination against the child and of indirect testing of the mother without her informed consent. Newborns at risk of HIV infection must be provided with adequate monitoring and care.

Collection of data on the prevalence of HIV infection that is as accurate as possible is important for targeting of limited HIV/AIDS prevention and control resources to the areas and people in greatest need. For this purpose, unlinked anonymous screening of pregnant women attending antenatal clinics has been conducted, or is planned, in many countries. In unlinked anonymous screening, samples for HIV testing are obtained from blood specimens collected from an individual for other purposes; all information that could potentially lead to the person being identified is eliminated ("unlinked") from the sample used for HIV testing.

The disadvantage of unlinked anonymous screening is that HIV-positive individuals cannot be identified for counselling and support. The advantage is that unbiased HIV prevalence data can be obtained. Voluntary confidential or anonymous HIV testing for identification, counselling, and support of those found to be HIV-infected is recommended to be made available wherever possible to those persons whose blood is being used for unlinked anonymous screening.

## Reproduction and HIV infection

If found to be infected with HIV, both men and women of reproductive age need to decide whether or not to have a child, and how to protect their sexual partner from HIV if he/she is not already infected. Below are some likely situations couples might face.

**If a woman is uninfected with HIV, but her sexual partner (male) discovers that he is infected:** it is impossible for the woman to become pregnant by her partner's sperm without running a high risk of becoming infected with HIV. This is because, as yet, there is no way of eliminating the virus from the infected man's sperm. However, the woman could receive artificial insemination with non-infected donor sperm, in countries where this is available. The woman should carefully consider whether she could look after the child adequately in the event of her infected sexual partner becoming ill, or dying.

**If a woman is infected with HIV, but her current (male) sexual partner is not:** the couple could still choose to have a child even knowing that the baby may be infected. However, the woman must be artificially inseminated with the sperm of her partner, since penetrative sexual intercourse (putting the penis inside the vagina) without the protection of a condom could result in HIV infection in the man.

HIV-infected women who become pregnant should be advised about the risks of having an infected child (see **What every mother-to-be should know**). Termination of pregnancy (abortion) should be offered as an option in countries where this is legal and safe, **but the final decision must be made by the pregnant woman.** Whatever decision she makes, special emotional support and practical advice should be provided including how to prevent other people becoming infected with the virus. All health care workers, particularly traditional birth attendants and midwives, should be trained to ensure continuing care and support, whilst ensuring privacy and confidentiality for the infected mother and her child.

# HIV/AIDS Counselling

## Request for help with a national report

The AIDS Unit in the Department of Health has sponsored the British Association for Counselling to produce a report about HIV/AIDS counselling. This report will include examples of good practice as well as make recommendations about how to improve existing counselling services. The writers are receiving a lot of information and ideas from counsellors but would also like to hear from the users of counselling.

Tim Bond, the Report Co-ordinator, commented

*I would particularly like to hear from people who have been on the receiving end of HIV/AIDS counselling. The counselling may have been provided by medics, social workers, paid or voluntary counsellors and may have been in relation to issues about being HIV positive or caring for someone who is. It would be very helpful to hear about good and bad experiences and any ideas about how to improve the counselling that is provided.*

*Anyone who is interested in responding may write directly to*

**TIM BOND, HIV Counselling Project,**

GRO-C

The identity of all respondents will be treated confidentially. All responses should reach Tim before mid September 1990.

# UNCIVIL LIBERTIES

**"My rights and liberties, as a person with HIV, are probably better protected here in the United Kingdom than they would be if I lived in almost any other country in the world." But that statement requires a lot of qualification, says**

GRO-D

The Haemophilia Society would like to thank AIDS MATTERS (May 1990, Issue 1) for permission to reprint this article.

The social, emotional, spiritual and physical violence towards people with HIV that has characterised so much of our own society's response to the disease must be resisted.

People like me, with a disease which could deprive us of health and eventually life can also be deprived of our jobs, homes, security, dignity, and the love of people we love and trust: everything, in short, that gives life quality and meaning.

This seems to me a perversion of everything I was taught to believe about the moral and social values of the culture I belong to and of human beings in general. My outrage and my sense of betrayal still burn, and I often wonder whether that incandescence is burning me up or keeping me alive.

The moral and social values that I took for granted are expressed in a number of international charters and treaties on human rights which governments subscribe to. In subscribing, they commit themselves not only to observe these rights, but to advance them.

Although governments which sign these treaties are legally bound by them, they are not automatically part of the law of each country. None of these rights exists in UK law. You cannot go to court in the UK to defend the rights you have under international law; you have to go to, for example, the European Court of Human Rights, and the UK government will abide by the court's decision.

This does not mean that human rights lack all protection in the UK. The UK has, for centuries, protected what we usually call civil rights or civil liberties by domestic laws which are the historical predecessors of the human rights enshrined in international law. It's ironic: we invented many of what are now called human rights, but UK law doesn't recognise them.

The absence of a specific code of rights makes it extremely difficult for a non-lawyer to know what his or her rights are. Acts of Parliament deal only with the general framework of legal rules and they usually empower Ministers to make specific rules in the form of what are called Statutory Instruments. But much of English law is made by judges – the common law: the accumulated decisions and judgements made by the courts over the years. Often you have to go to court to establish what your rights are.

There is, for example, in common law, a duty of confidence. Recently, a health authority sought, through the courts, to restrain a national newspaper from publishing information about two doctors with an AIDS diagnosis who were employed by that health authority and still practising as doctors. The information had been obtained by the newspaper as a result of another health authority employee breaching the confidentiality clause in his contract.

The court found that "preservation of confidentiality is the only way of securing public health" and that this over-rode the newspaper's claim that publishing the information was in the public interest.

It was fortunate for those two doctors that their employer took up their case. For many people with AIDS, the cost of pursuing an action through the courts to establish their rights would be prohibitive. Perhaps a greater disincentive is the risk that a court case would focus public attention on them, and expose them to exactly the kind of social violence in the form of indiscriminatory behaviour, which may have prompted them to go to court in the first place.

Our government did not escape AIDS panic altogether. In 1985 it introduced a Statutory Instrument which provided, under certain circumstances, for the compulsory medical examination of people with HIV or AIDS and the compulsory removal of such a person to hospital. These measures have been used once, ignominiously, in Manchester and were withdrawn on appeal.

I regard it as an infringement of civil liberties that a person with a life-threatening illness can be evicted from their housing or be pressured into leaving their job simply because of their condition.

I regard it as an infringement of civil liberties that a prison inmate with HIV, who has already lost his freedom, should be further punished by ostracism or isolation within the prison community.

I regard it as an infringement of civil liberties that a person with AIDS can not receive sufficient financial support from the state to allow him or her to maintain the quality of his or her life at a time when quality is the most cherished thing because there is precious little time left in which to enjoy it.

I regard it as an infringement of civil liberties that a pregnant woman with HIV should be actively discouraged from having children.

I regard it as an absurdity that health authorities are having to finance special centres because ordinary dentists refuse to treat people with HIV.

I used to forgive prejudice – prejudice in its literal meaning of forming opinions or judgements without proper information – and in that sense, five or six years ago, prejudice was understandable: there was a new disease around, which seemed to be spreading rapidly, which suggested it could be spread easily. Who couldn't be forgiven for being so scared that, confronted with a person who had this disease, they would suspend all their normal respect and compassion for someone terminally ill?

Even if you wanted to defend your rights under international law, taking a case to the European Court of

*(Continued on following page)*

**"I used to forgive prejudice. I don't forgive it any longer. How long is it going to take to educate people?"**

# JONATHAN COOPER MOVES ON

Since the Bulletin is a formal record of Society activities it would be remiss not to include a very full tribute to Jonathan Cooper for the work he has done for the Society over the past three years.

It has always been the case that we have operated on a shoe-string and it came as a considerable breakthrough when funding became available through the good offices of **The Readers' Digest** and **International AIDS Day** which enabled the Society to consider a new post to provide special help to the General Secretary with issues arising from HIV and AIDS infection in people with haemophilia. We were singularly fortunate to be able to recruit Jonathan who brought to this new and exciting task enthusiasm, sensitivity and understanding.

### OUTSTANDING CONTRIBUTIONS

During his time with the Society he has made many outstanding contributions to our life and work. We will highlight a few here which the General Secretary has described as 'landmark' pieces of work in the history of the Society.

One of the first original pieces of work was the Benefits Handbook for people with HIV. Despite the fact that the regulations have changed since its publication it was a market leader in its day and, strangely, is still often requested today! Jonathan also undertook as part of his work the first UK survey of Haemophilia Centres to be undertaken personally by the Society. This proved an invaluable base for our ongoing work and for our work in producing a new Directory of UK Haemophilia Centres.

### PIONEERED

Jonathan also pioneered the Symposium on Paediatric HIV which was held in Glasgow in 1989 – the first such symposium to be held in the UK and, appropriately, this was sponsored by the Society as the single group with the largest number of HIV positive patients.

Finally, Jonathan was instrumental in getting our new booklet 'Safer Sex – The Choice is Here' off the ground – undertaking the negotiations with the Health Education Authority, the publishers, the designers, the artists, and so on. In addition Jonathan has worked closely with the World Federation of Hemophilia in preparing an international manual on safer sex and AIDS in haemophilia.

### GREAT DEAL BESIDES

It goes without saying that Jonathan did a great deal besides – especially in opening up and forging new links with HIV and AIDS organisations and making the work of the Society more widely known throughout the whole new world of what has become the AIDS industry. Very special relationships were also created with large numbers of anxious patients and their loved ones in connection with their anxieties.

All in all Jonathan was a tremendous asset to the work of the Society and a wonderful colleague and friend. We will all miss him a very great deal and when he leaves he will take with him the very best wishes of us all for his new life in the legal profession.

**(Footnote: Graham Barker, Jonathan's successor, started work on 16 July)**

**NR**

# UNCIVIL LIBERTIES *(Continued from previous page)*

Human Rights is a very lengthy and tortuous process. If you have HIV or AIDS it is unlikely that your stamina, or perhaps your lifespan, could accommodate such an ordeal. The process itself discriminates against people with life-shortening illness.

The International Covenant on Civil and Political Rights states: "All persons are equal before the law and are entitled without any discrimination to the equal protection of the law." People with HIV cannot be equally protected by the law when there are so many compelling disincentives to go to the courts in the UK and when you are likely to be dead before an international court reaches a decision.

All the treaties on human rights allow governments to suspend some rights in the event of a public emergency which "threatens the life of the nation". Some governments, in the grip of AIDS panic, have done exactly that.

Despite advice from the World Health Organisation that it is not in the interest of public health, thirty-five member countries place border restrictions on the entry of people with HIV. Other countries have introduced compulsory testing, compulsory notification of people with HIV or AIDS to the authorities, compulsory detention of such people and compulsory deportation of such people.

To its credit, the UK government has resisted pressure, and sometimes considerable pressure, to introduce similarly coercive legislation here, although it has resisted out of pragmatism – it believes such measures would drive HIV underground – rather than out of respect for human rights.

I don't forgive it any longer. Nearly 10 years into the epidemic, we still do not live in an AIDS-educated society. How long is it going to take to educate people that those of us with HIV or AIDS need society's protection and generosity rather than the burden of its meanness and parsimony!

The government rejects calls for legislation to protect people with HIV and AIDS from discrimination. It knows that discrimination occurs but it argues that legislation giving special and specific protection to people with HIV and AIDS might be counter-productive by aggravating resentment, and thus discriminatory behaviour, by other social groups not similarly favoured by legislation. It argues also that existing legislation provides sufficient protection.

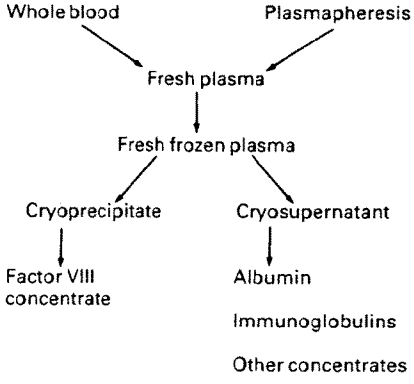
I don't want the government to give me rights that other people do not have, but I do want to share in the rights that everyone else enjoys, and I want my ability to do that protected. By not legislating, the government, by default, endorses and legitimises all those acts by individuals and institutions which say, in effect, that people with this disease aren't worth much so their rights don't have to be respected.

But, in the end, I can't rely on the government to legislate. It won't, unless public opinion demands it. Rights and liberties aren't bestowed, they are achieved. For some of us, AIDS has made those rights and liberties extremely fragile. We have to rely on those of you who do not have HIV. Mark Twain said "It is a worthy thing to fight for one's own freedom; it is another sight finer to fight for the freedom of another man."

**GRO-D**

# PLASMA, PLASMA PRODUCTS, AND INDICATIONS FOR THEIR USE

Hannah Cohen, Peter B A Kernoff




Plasma fractionation pathways.

Modern methods of fractionating plasma into its components are based on the pioneering work of Cohn and his colleagues during the second world war. Since then world demand for plasma products has increased so that it now exceeds that for cellular components of blood. The concept that optimal use of plasma is achieved by fractionation is now firmly established, and a wide range of products is available for therapeutic use. We shall consider all these products except albumin.

*Plasma product concentrates: indications for use*

| Plasma product concentrate | Indications for use |
|---|---|
| Human factor VIII | Congenital deficiency (haemophilia A, von Willebrand's disease) |
| Porcine factor VIII | Factor VIII inhibitors |
| Factor IX (prothrombin complex concentrate) | Congenital deficiency (haemophilia B)<br>Reversal of oral anticoagulant overdose<br>Congenital deficiencies of factors II and X<br>Factor VIII inhibitors<br>Severe liver disease |
| Factor VII | Congenital deficiency<br>Reversal of oral anticoagulant overdose<br>Severe liver disease |
| Immunoglobulin | Passive prophylaxis<br>Congenital agammaglobulinaemia or hypogammaglobulinaemia<br>Some types of immune thrombocytopenic purpura<br>? Other acquired immune disorders |
| Antithrombin III | Congenital deficiency<br>? Disseminated intravascular coagulation, ? Liver transplantation, ? Other acquired deficiency states |
| Factor XI | Congenital deficiency |
| Factor XIII | Congenital deficiency |
| Activated prothrombin complex concentrate | Factor VIII inhibitors |
| Protein C | Congenital deficiency |
| C1 esterase inhibitor | Hereditary angioedema |
| α1 Antitrypsin | Hereditary deficiency (emphysema, cirrhosis) |
| Fibronectin | ? Acquired deficiency states |

Products listed include those manufactured within the NHS and commercial companies.

Most therapeutic plasma products are manufactured from pools of plasma derived from many thousands of donors. Although strenuous efforts are being made to achieve self sufficiency, the United Kingdom is still substantially dependent on imported products that originate mainly from commercial companies in the United States. In the past the safety of imported products was inferior to that of those made within the NHS, but this is not now the case. All products made from large pools of donor plasma are derived from individually screened donors and made by processes that inactivate or remove (or both) any contaminating viruses. Although the risks of viral transmission are small, there can never be absolute assurance of freedom from risk. It should also be appreciated that there are few absolute indications for treatment with plasma and plasma products and that some widely used products are unlicensed and prescribed for a "named patient" or under "Crown immunity." Especially in acquired disorders, in which sound evidence of efficacy is usually weakest, clinicians should take careful account of these factors before treating patients and be aware that inappropriate use is wasteful of a scarce resource for which demand exceeds supply.

## Fresh frozen plasma

*Half lives of infused coagulation factors contained in fresh frozen plasma*

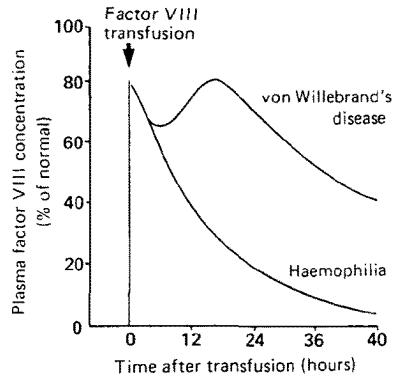
| Factor | Half life of infused factor (hours) |
|---|---|
| I (fibrinogen) | 72-120 |
| II (prothrombin) | 72 |
| V (proaccelerin) | 12 |
| VII (proconvertin) | 2-5 |
| VIII (antihaemophilic factor) | 8-12 |
| IX (Christmas factor) | 24 |
| X (Stuart-Prower factor) | 24-40 |
| XI (plasma thromboplastin antecedent) | 60-80 |
| XII (Hageman factor) | 40-50 |
| XIII (fibrin stabilising factor) | 216-240 |
| Antithrombin III | 45-60 |
| Protein C | 8 |
| Protein S | 12-22 |
| Fibronectin | 24-72 |

Half lives of coagulation factors may be shortened when there is increased consumption—for example, in disseminated intravascular coagulation or during thrombotic episodes.

Fresh frozen plasma is obtained either by separation of plasma from whole blood or by plasmapheresis. In either case the plasma is frozen as rapidly as possible after collection to preserve labile coagulation factors.

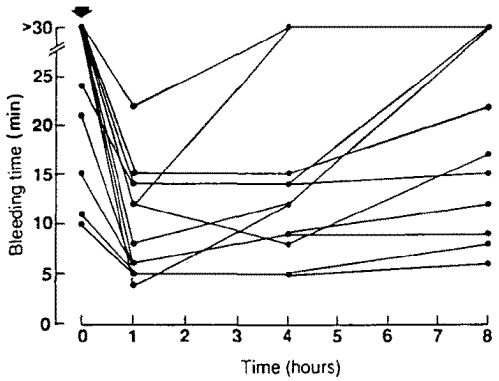
Despite its widespread use, firm indications for giving fresh frozen plasma are few. It is helpful in the treatment of congenital deficiencies of coagulation factors (for example, that of factor V) when there is no specific factor concentrate available. Used aggressively, sometimes with plasma exchange, it is valuable in patients with thrombotic thrombocytopenic purpura and similar syndromes. Fresh frozen plasma may be used for the reversal of the effects of oral anticoagulation associated with serious bleeding if factor IX or factor VII concentrates are not available and to correct depletion of coagulation factors in bleeding associated with thrombolytic treatment. Despite being widely advocated for patients with multiple coagulation defects (as in severe liver disease, disseminated intravascular coagulation, and patients who have had massive transfusions), the effect of fresh frozen plasma is poorly defined and its use should probably be confined to patients with severe abnormalities on coagulation testing. What is clear is that if any benefit is to be obtained fresh frozen plasma must be given in adequate quantities and rapidly—perhaps four donor units (800 ml) over one to two hours, and then repeated. There is no justification for its use as a volume expander; synthetic colloids are more effective, cheaper, and safer.

## Cryoprecipitate




Characteristic responses to plasma products containing factor VIII in haemophilia A and von Willebrand's disease.

Cryoprecipitate is prepared from fresh frozen plasma by slow thawing at 4-6°C. The resulting precipitate ("cryo") is then separated from the supernatant and refrozen for storage. Cryoprecipitate contains factor VIII, fibrinogen, von Willebrand factor, factor XIII, and fibronectin in higher concentrations than they are found in plasma, and its preparation is normally the first step in plasma fractionation. When used directly it is usual to thaw and pool 10-30 donor units for an adult patient, but the dose depends on the circumstances. In the past cryoprecipitate was sometimes preferred to factor VIII concentrate as it was thought to be safer because it was made from smaller pools of donor plasma, but this is no longer so since the advent of effective sterilisation procedures for concentrates.

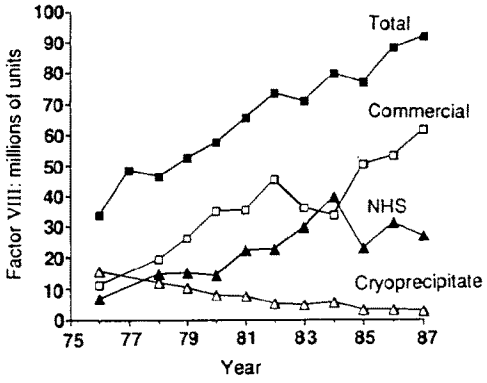



Correction of bleeding times in uraemia with desmopressin (DDAVP).

Cryoprecipitate is used to promote haemostasis in various conditions, but which of its several components is functionally important is often uncertain and this makes monitoring and assessment of dosage difficult. When used in von Willebrand's disease its content of high molecular weight multimers of von Willebrand factor may be of key importance. This may also be the case in chronic renal failure and some congenital platelet disorders, in which there is good evidence that it corrects abnormal bleeding times and controls bleeding. Mainly anecdotal evidence suggests possible benefit in some patients with disseminated intravascular coagulation, advanced liver disease, and the microvascular bleeding syndrome associated with massive transfusion. The therapeutic efficacy of cryoprecipitate is dose dependent, so increased doses and repeated treatment may be needed if initial treatment seems to fail.

The drug desmopressin (DDAVP) has been shown to have a similar effect to cryoprecipitate for several conditions and is clearly preferable for reasons of both cost and safety when its effect is equal.

## Factor VIII concentrate



Amount of factor VIII used in the United Kingdom.

Factor VIII concentrate is the therapeutic product of choice for patients with haemophilia A (factor VIII deficiency) and has superseded fresh frozen plasma and cryoprecipitate in its management. It is now also preferred to cryoprecipitate (for reasons of safety) for most patients with von Willebrand's disease who require treatment with plasma products. Like most other concentrates it is supplied as a freeze dried powder that is reconstituted with a small volume of sterile water before intravenous injection. Factor VIII has a short half life (about 12 hours in vivo), so repeated injections are necessary for a sustained effect.

Used appropriately factor VIII is of great benefit to haemophiliacs, for whom it may be regarded as an essential drug. It both prevents and stops bleeding, prevents crippling arthropathy, and—as many patients are able to treat themselves—allows them to lead normal lives. Although haemophilia A is a rare disease, demand for factor VIII is the main force behind the world's plasma fractionation industry, and the economics of supply of all other plasma products are critically dependent on this demand. Recombinant (synthetic) factor VIII has recently been introduced in clinical trials. Though it may take several years for it to become generally available, it has the potential for causing serious imbalances in the fractionation industry with possible adverse effects on the availability and pricing of other plasma products.

*Estimated consumption of factor VIII by country: 1987.*

| Country | Factor VIII (millions of units) | Population (millions) | Consumption per head (units) |
|---|---|---|---|
| West Germany | 211·0 | 61·0 | 3·45 |
| Sweden | 24·8 | 8·4 | 2·95 |
| The Netherlands | 36·5 | 14·4 | 2·53 |
| Canada | 62·7 | 25·6 | 2·45 |
| United States | 550·0 | 239·3 | 2·30 |
| Spain | 65·0 | 38·8 | 1·67 |
| United Kingdom | 92·0 | 56·0 | 1·64 |

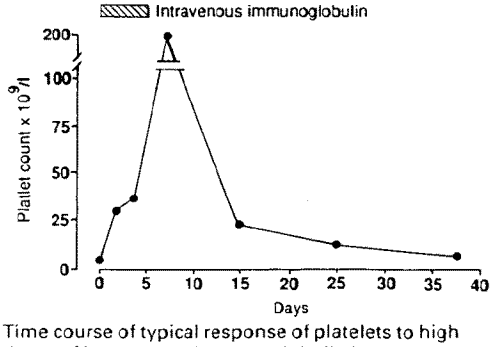
## Factor IX concentrate


Destructive haemophilic arthropathy, which was common among patients with severe haemophilia A and B before treatment with replacement of factors was possible.

The factor IX concentrate (prothrombin complex concentrate) that is made within the NHS contains coagulation factors IX, X, and II, and it is used for the treatment of haemophilia B (factor IX deficiency) and congenital deficiencies of factors X and II. Given with factor VII concentrate it is more effective than fresh frozen plasma in controlling the serious haemorrhage that can be caused by overdoses of anticoagulants and may sometimes be useful in treating the bleeding associated with advanced liver disease. It should be appreciated, however, that in liver disease it can correct only part of the overall haemostatic abnormality and carries a risk of provoking disseminated intravascular coagulation. Used in high doses factor IX concentrate may result in thrombotic episodes. In an attempt to reduce the risk of such episodes, commercially made concentrates containing factor IX alone are undergoing clinical trial.

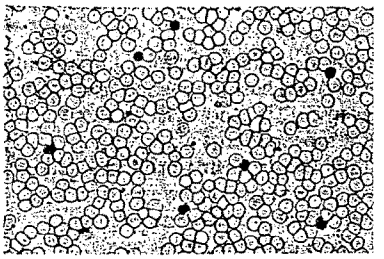
Occasionally it is used to treat patients with haemophilia A who have circulating antibodies (inhibitors) to factor VIII because of its supposed inhibitor bypassing activity. Commercial "activated" prothrombin complex concentrates are also available. Factor IX concentrate also contains the physiological coagulation inhibitor proteins C and S. Its use in the treatment of deficiencies of these proteins is, however, still undefined, and a commercially made protein C concentrate has recently become available for clinical trial.

## Immunoglobulins



Time course of typical response of platelets to high doses of intravenous immunoglobulin in adult (chronic) idiopathic thrombocytopenic purpura.

• *Specific immunoglobulins* are obtained from donors whose plasma contains selected high titre IgG antibodies, as a result either of previous infection or of active immunisation. Usually given by intramuscular injection, preparations are available for use in the passive prophylaxis of varicella-zoster, tetanus, hepatitis B, cytomegalovirus, and other infections. Immunity lasts a few weeks. Anti-Rhesus D is used in the prevention of primary Rh immunisation and haemolytic disease of the newborn.



Kleihauer technique showing fetal cells (darkly stained) in maternal circulation of Rh D negative woman. From this, the dose of Rh D immunoglobulin necessary to prevent primary immunisation can be assessed.

## Other plasma products

The amount of factor VIII used in the United Kingdom is taken from the United Kingdom Haemophilia Directors' Statistics, and the graph of correction of bleeding times in uraemia with desmopressin was adapted from Mannucci PM, Remuzzi G, Pusineri F, *et al.* Deamino-8-D-arginine vasopressin shortens the bleeding time in uraemia. *N Engl J Med* 1983;308:8-12.

• *Non-specific ("normal") immunoglobulin* is derived from the pooled plasma of non-selected donors and contains antibodies to all the viruses prevalent in the donor population. One of the main indications for its intramuscular use is in the passive prophylaxis of hepatitis A. Preparations made for intravenous use have the advantage that much larger doses may be given with minimal discomfort to the patient. Intravenous immunoglobulin was introduced primarily for the treatment of congenital hypogammaglobulinaemia, but its range of application has now broadened considerably to include immunomodulation, especially in some autoimmune disorders. A particular indication is for some types of immune thrombocytopenic purpura in which high doses of intravenous immunoglobulin are used to induce (usually short term) rises in the platelet count. Its mode of action is not certain but probably includes blockage of the mononuclear phagocytes. Its clinical uses are increasing rapidly, and it represents an important area of growth in treatment with plasma products.

Several other plasma products have recently become available, and there is little doubt that these concentrates are effective in raising subnormal concentrations of circulating plasma factors. Except in the rare congenital deficiency states, however, convincing evidence of clinical benefit is generally weak, and indications remain ill defined.

Hannah Cohen, MD, is senior lecturer in haematology at St Mary's Hospital Medical School and the Central Middlesex Hospital, and Peter B A Kernoff, MD, is director of the Haemophilia Centre and Haemostasis Unit, Royal Free Hospital, London.

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# David to visit Scotland in October

You may recall from our reporting of CERT that the Society decided to embark on a mission to 'nourish and foster' local Groups. After some months of planning Scotland will be the first to benefit from this exercise during October when the General Secretary will spend a week in his 'homeland' giving time to both local Groups and members of the Society. While we are not able to specify where he will be available the diary for the visits is as follows:

**Tuesday October 23:**
Aberdeen – Grampian Group.
**Wednesday October 24:**
Dundee – Tayside Group.
**Thursday October 25:**
Perth – Perth Group.
**Friday October 26:**
Glasgow – West of Scotland Group.
**Saturday October 27:**
Edinburgh – SE Scotland Group.

It is the General Secretary's intention to be available for Society members during the course of each afternoon – **you should note most especially that this will be the opportunity for those who are not connected with the local Group to make any points to the General Secretary.** This is a unique opportunity for people in the areas mentioned to have direct contact with David Watters. If it is successful it will be repeated throughout the country in due course.

Evenings will be spent with local Group Committee members and, to round the week off, all the local Group Officers will meet on Sunday October 28 for a closing session in central Scotland.

**EDITOR: Andy Cowe**

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



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