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INFECTED BLOOD INQUIRY

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The Bulletin

1995 – No 4

HEPATITIS C CAMPAIGN

This edition of the Bulletin has been delayed to allow us to report the latest developments in the hepatitis C Campaign.

The interim hepatitis C impact report by the Society looking into the effects of the virus on people with haemophilia has been published and copies sent to Ministers, MPs and the press. This report was the subject of a parliamentary question to the new Minister of Health, John Horam, who promised to examine it thoroughly.

This was followed by an adjournment debate in the House of Commons on 13th December. During the debate, Mr Horam indicated that the government were willing to consider proposals for helping people with haemophilia infected with hepatitis C.

As the Bulletin goes to print the Manor House Group are meeting with the Secretary of State for Health Stephen Dorrell.

The Early Day Motion in the House of Commons has now been signed by 250 MPs supporting our cause. These MPs are of all parties, and as the numbers increase so does the likelihood of government action.

These are all important developments. But more still needs to be done. It is particularly important that more MPs sign the Early Day Motion supporting the claim of people with haemophilia for financial help. If you haven't already done so write to, or even better, visit your MP. Ask them if they have signed the Early Day Motion, or supported our cause by writing to the Health Minster. Your support is vital to success in the campaign, and the more people contacting MPs the more likely they are to act.

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A SEASONAL MESSAGE

from Society Chairman the Revd Prebendary Alan Tanner

As we celebrate the Christmas festival and look forward to the beginning of another year, we do well to pause and remember with gratitude all who have contributed to the substantial progress in our work during 1995.

However, while we recognise the substantial improvements in the service provided for people with haemophilia and their families, we are very much aware that there is still much to be done. For example, the campaign for recompense for people with haemophilia with hepatitis C infection is receiving support from many members of parliament, but the strength of our own case has yet to be accepted by the government, so our efforts must be maintained in these crucial days ahead.

Meanwhile we remember our commitment to respond to all who look to us for help, especially those who feel lonely or sad at the holiday season.

The Christmas message tells us of light shining in darkness and of hope brought to a troubled world. In sending this message to all members of the Society I add my own prayers that we may be steadfast in our efforts to strengthen and care for each other during this coming year.

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EDITORIAL by Bulletin Editor Andy Cowe

1995 has been yet another year of achievement for the Haemophilia Society. Our services to members are growing, with more people than ever attending our "Haemophilia Day" and "Hepatitis Day" meetings. We are giving more and more information and advice in answer to telephone enquiries to the national office. Our research activities have increased, particularly in the important area of Hepatitis C. Our lobbying and campaigning have helped to maintain standards of care locally, and to keep haemophilia issues in the forefront of government's and media attention. We have played our part in Europe and world-wide and have established a twinning link with our Russian counterparts. These are but a few examples which show the level of activity of our Society.

None of this would have been possible without widespread support. To everyone who has donated funds, whether by personal gift, fund-raising events, or corporate sponsorship, we say thank you for your generosity. Your help has made a difference. To those who have given their time and used their knowledge and skill in local groups, at national meetings or in writing for our publications we say thank you for your dedication and enthusiasm.

In the course of the year we have said farewell to some staff and welcomed others. Throughout the year, Susan Archer and Graham Barker have continued as the mainstays of the national office and they and all their staff deserve our heartfelt thanks for their commitment, guidance and expertise.

To everyone associated with the Haemophilia Society we send every good wish for 1996.

Publications and Services available from the Haemophilia Society

Publications

The Society produces the range of books, booklets and leaflets listed below to help people with haemophilia.

- Introduction to Haemophilia
- Joint Care and Exercises
- The Essentials of Haemophilia Care
- Teaching Children with Bleeding Disorders
- Haemophilia and Hepatitis C
- Children's Haemophilia Book
- Will making guide
- NHSME Patient Perspective Booklet
- Past copies of the Bulletin

Services

The Society works to help people with haemophilia from its national office and also via the local Groups. The services currently available from the national office are:

- Information and help with benefits, in particular Disability Living Allowance
- Hardship grants
- Armourpage service
- Caravan Holidays
- Adventure Holidays for children
- Fund-raising support
- Assistance with media enquiries
- Information on treatments and blood products
- Travel insurance advice
- Information on travel regulations/restrictions
- Haemophilia Days
- One-off meetings on specific issues, such as hepatitis.

For further information about the above services, or to check on the availability of Society publications, please contact the national office.

BPL
BIO PRODUCTS LABORATORY

We extend our grateful thanks to the Bio Products Laboratory who have kindly donated a sum to pay for the publication of this edition of the Bulletin.

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VAT ON RECOMBINANT FVIII

The Society has been pushing hard to persuade Customs and Excise to reverse its recent decision to impose VAT on recombinant factor VIII from November 1st.

Recombinant factor VIII is not classed as a blood product because it is not derived from human plasma, so Customs and Excise have decided that it is liable for VAT at 17.5%.

Just before the budget the Society wrote an open letter to the Chancellor, Kenneth Clarke, asking him to reverse this decision as it pushes the cost of recombinant factor VIII out of the reach of treatment centres.

"We will continue to press Customs and Excise on this issue," said Graham Barker, Society Director of Services. "Recombinant products are free from the risk of blood-borne viral transmission and so the Society would prefer all people with haemophilia to be treated with these products, particularly children. We fear that the imposition of VAT on these products which are already expensive will mean that children will not receive access to them.

"We hope, that with continued pressure from the Society, Customs and Excise will reverse their decision."

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HEPATITIS C LEGAL NOTES AVAILABLE

The Haemophilia Society has available, on request, solicitor's notes on the circumstances surrounding one member's successful claim for medical negligence after infection with hepatitis C. This member has kindly agreed to share her experiences with other people who may be considering litigation.

Please contact the Society if you would like a copy of the notes.

We have had a number of requests for advice and information about legal action. We are aware that it is often difficult for people to make a decision on the basis of limited experience of legal matters. Although every case is different, it is hoped that these notes may help people to reach a decision about whether or not to proceed.

We also know that some people are still being told their hepatitis C results. The Society feels it is important to remind people considering legal advice about the time limits which apply to such claims. The following advice has been sourced from a firm of solicitors.

"By law, if a person has been "injured" as a result of medical negligence, then a claim must be made within three years of the date of the "injury" (ie the date of infection with hepatitis C). Most people are completely unaware of being infected at that time. In such cases, the three year time period does not begin until the date they first became aware that they have been infected. This will usually be when a person is informed of a positive test result".

Individuals concerned can contact a lawyer of their choice. The Society has a list of solicitors available who have some experience of dealing with cases in this area.

If you have experience of any of these or other solicitors that you feel we should hear about, please let the Society know.

MAJOR CHANGES TO BLOOD SERVICE

Changes to the structure of the blood service were announced by the Secretary of State for Health Stephen Dorrell in November.

The changes will remove the bulk testing and processing functions from five regional centres: Lancaster, Oxford, Cambridge, Liverpool and Plymouth. Also the administrative functions of the 13 existing regional centres will be concentrated into three zonal centres, based in Bristol, Leeds and London. These changes are expected to lead to a reduction in staffing levels of around seven per cent over the next three years - approximately 300 posts.

The Secretary of State also announced a new Blood Donor's Charter and National User Group. The Charter sets standards of what donors can expect, shorter waiting times to give blood, higher standard of premises and greater use of blood mobiles. The User Group, made up of clinicians rather than patients, will monitor the service provided to hospitals by the blood service. It will be chaired by Professor Edward Gordon-Smith, professor of Haematology at St George's Hospital in London.

In addition, Mr Dorrell announced that a new national computer system will be introduced to allow blood stocks to be managed on a national basis. Mr Dorrell also pointed out that the blood authority is increasing the resources it commits to research and development. It has appointed a national co-ordinator for Research and Development and is developing centres of research excellence at Cambridge and Bristol.

HAEMOPHILIA SOCIETY BLOOD PRODUCTS POLICY

The Haemophilia Society has produced a revised policy towards blood products. The new policy states:

- It is the policy of the Haemophilia Society that blood products used in the treatment of haemeophilia throughout the United Kingdom must be safe from contamination by all pathogenic agents. All blood plasma must be screened for all known contaminants using the best available techniques.
- The option of prophylactic treatment should be available to all with haemophilia. It is the treatment of choice for children, and must be considered for older patients when clinically indicated.
- All people with haemophilia should have the opportunity to use recombinant products. In the interim, only high purity products should be used and in the case of people who are HIV positive, monoclonal products should be used. The use of intermediate purity products should be phased out.
- The Society upholds the principle of a voluntary based system of blood donation within the UK. The Society supports the principle of self sufficiency in blood products as defined by the UK government: namely that self-sufficiency means that supplies of domestically sourced blood products should be sufficient, both in range and quantity, to meet the needs of all patients for whom they are clinically indicated.
- Financial constraints should not be a limiting factor in achieving any of these objectives.

This policy clarifies the Society's position following the introduction of new products, such as recombinant clotting factors. It demonstrates a firm commitment to the use of the safest products possible, and that prophylaxis should be available to all, especially to children.

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SECTION 64 GRANT

The Society is currently in receipt of a Section 64 project grant from the Department of Health to support its hepatitis activities. The money is being used to provide information, advice and support to members infected and affected by hepatitis. This money cannot however be used to make cash grants to individuals infected with hepatitis. The Department is at present considering the Society's application for a second year's funding (1996-7). If this is successful we hope to be able to increase the activities and information available to members.

OPENING OF CANTERBURY HAEMOPHILIA CENTRE

GRO-D

The new Haemophilia Centre in Canterbury was formally opened by Her Royal Highness the Duchess of Kent on 19 September. The Duchess was given a tour of the new centre and laboratory by the Director, Dr Mark Winter, and saw many exhibits and demonstrations organised by the young children with haemophilia who attend the centre.

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BIRCHGROVE COMPLEMENTARY THERAPY WEEKEND

The Birchgrove Group successfully held a Complementary Therapy Weekend for those affected with haemophilia and HIV. The weekend took place on the 13th and 14th of October in the Metropole Hotel in Birmingham. Over fifty people got together to have an introduction to some of the many therapies that were on offer.

These included aromatherapy, amorali, partial massage, spiritual healing, hypnotherapy, Alexander technique, shiatsu, relaxation massage, homeopathy and sessions on positive thinking and long term survival.

Overall the opportunity to meet people and to discuss issues and problems was a valuable activity that was enjoyed by all those who attended the weekend.

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THE RED RIBBON PAGE

Long Term Survival

The long term effects of HIV on individuals who are long term survivors of this virus, are relatively unexplored. Once again many people with haemophilia are boldly going where no-one else has gone before.

People who have coped with their HIV status relatively well for the early years of their diagnosis can begin to encounter a type of "mid-life crisis". Ten years after infection you begin to think "Why am I alive, when so many others have died? Maybe I have to be next, it has to be my turn soon! With so many people with haemophilia having died it's inevitable that HIV will get me next!"

These disturbing thoughts and feelings can begin to surface for long term survivors because of the time factor, ten years can give you a long time to think! Obviously, not all long term survivors react in the same way. Some people experience extreme and continued concern about their health, even though they may not have developed new symptoms or had a decrease in their general well-being. Some people experience a gradual and recurring depression that demotivates and disables them, there are so few encouragements to survive, so little good news in a wealth of grim statistics. Some people are forced back into denying that HIV is present in their system, a denial of their health situation which at other times they have fought to understand.

For many people the overall progression of HIV disease appears to lead to a reduction in their energy. People who felt able to undertake jobs, families and normal lives become increasingly limited in the amount of stamina and fitness available to them. "I just can't do it any more!" "I feel like a clock which is slowly running down" or "I always feel like I've had several late nights, and not enough sleep to recover".

At some time in the progression of HIV disease, long term survivors begin to make changes to their lives which they feel reflect the situation that they are in. People often reduce or give up work, this of course not only has financial implications but has a great significance to a person's overall state of mind. Others can create dramatic changes within relationships with family or friends and this is often catastrophic for people's ability to lead a stable stress-free life.

Long term survivors often begin to need increased support, whether from health professionals, therapists, friends or family. The reasons for this increasing dependance and lack of ability are difficult to pinpoint. It may be physical, due to the increased viral load in a person's system, a slow degeneration of general health and well-being or it may be psychological, an inevitable response to the years of uncertainty and fear.

Without intervention, this process of mental and physical deterioration can spiral down to severe health problems, AIDS related illnesses and a physical and psychological situation which it may not be possible to recover from. Because illness has not become a problem for those with HIV in the early years, it does not mean that health care and support from one's family and community is not necessary for actual moments of crisis.

Shared Rights Shared Responsibilities

This year's theme for World AIDS day sounds like common sense. The rights and responsibilities of the HIV community and the rights and responsibilities of the wider society balanced together. But perhaps there is a darker message beneath the slogan.

Many members of the World Health Organisation were very keen on this particular World AIDS day theme. Their countries are facing an AIDS crisis, populations devastated by AIDS, whole communities where the problem is so endemic that survival, rather than good health becomes the priority.

The solution to the crisis is to ensure that those affected bear the responsibility to protect those who are not infected. Those who have the virus should isolate themselves from those who do not. Ensuring that those not affected retain the "right" to carry on regardless in supposed safety.

The belief is that as long as those who are HIV positive "keep it to themselves" then there will be no problem. We should all be able to see the sense in this argument. It is attractive because of its simplicity and directness. But life is never simple, and sexual politics are seldom direct.

The rights and responsibilities of HIV are not shared equally. If you are not HIV positive then the message is clear. You have a responsibility to protect yourself and you have a right not to exercise this responsibility. Whether it's true love or a one night stand - your responsibility is to look after yourself and your right is not to bother.

But if you are HIV positive can the same message be shared? "Your responsibility is to look after yourself and your right is not to bother?" A positive person who put themself first in this way would be seen as a real risk to society. It sounds like this person should be locked up pretty rapidly! And in some countries that's what they do.

You know your rights, you have the right to remain silent, anything you say will be taken down and used in evidence against you!" I can hear the crash of the cell door slamming, the distant sound of the key clattering between the grating of a drain.

In our society, rights for positive people are questionable concepts. If you are sacked because you have HIV - you have no rights, if you are refused treatment by a dentist - you have no rights, if you are refused a mortgage or a loan - you have no rights.

But you do have a responsibility to tell the person you want to have sex with, "By the way, before you get too excited, I thought I should just mention that I've got HIV." You do have a responsibility to tell nurse who is going to take blood, "Don't you think you should be wearing gloves? After all one of us might be positive!"

Society cannot share the realities of HIV and AIDS. These supposed rights and responsibilities are different concepts depending on which side of the divide you stand. But those with thevirus do have a responsibility to be aware of the changing world in which they live. Society's attitude is hardening, the problem belongs to the few, those who are at risk are irresponsible, society has the right to be safe. Unlike responsibilities which often arrive unbidden, rights need to be worked for. The right of those with HIV to be equal members in an open society is a very distant goal, but it is perhaps an ideal which we should all share.

The articles in this edition's Red Ribbon Page have been submitted to the Bulletin by members of the Birchgrove Group.

VACCINATION

Vaccination against diseases is standard practice in the United Kingdom. The Bulletin asked Dr Dolan of the Nottingham Haemophilia Centre to explain the approach to vaccinations for people with haemophilia and associated bleeding disorders.

A key defence against microorganisms (bacteria and viruses) is the production, by the immune system of special proteins called antibodies. These antibodies are usually generated after exposure to a particular germ by infection. Many though not all such antibodies can subsequently recognise and attack the same microorganism on re-exposure. Immunity can be developed by deliberately exposing the immune system to a bacteria or virus and this is the principle of 'active' immunisation or vaccination.

The aim of modern vaccines is to deliver the bacteria, bacterial toxin or virus in a form which will not cause serious illness in the recipient. This can be done by producing vaccines from killed, inactivated organisms (eg whooping cough, typhoid fever, influenza and rabies) or by using only specific parts of certain bugs (eg meningococcus, pneumococcus, diphtheria and tetanus). These methods are however not suitable for all vaccines and some (eg measles, rubella, mumps, tuberculosis and yellow fever) need 'live' organisms to produce effective antibodies. These germs are 'attenuated' ie they have been treated in such a way that their ability to cause actual infection when faced with a competent human immune system is greatly diminished. Unfortunately some of the vaccines in this latter category can pose problems for HIV-positive and other immunosuppressed individuals.

The majority of the vaccines are delivered to the antibody-producing cells of the body by injection. Injections can be given into muscles (intramuscular), under the skin (subcutaneous) or into the skin (intradermal). Intramuscular injection can be substituted in patients with haemophilia or other bleeding disorders where the subcutaneous or intradermal routes are acceptable alternatives.

Individuals with haemophilia have the same requirements for vaccination as anyone else but there are some important potential additions/modifications to standard advice:-

Vaccination against hepatitis

Modern factor concentrates have been subjected to very effective procedures to prevent transmission of hepatitis viruses. Nevertheless, all regular recipients of blood products should be vaccinated against hepatitis B. This should preferably be before first exposure to factor concentrates but this is not always possible. Levels of immunity usually wane after several years and each Centre will have a policy for reassessment and re-vaccination. This policy should also cover carers and families.

There has been great interest in cases of potential transmission of hepatitis A by certain factor concentrates in recent years. This has led to some Centres routinely vaccinating those who do not already have immunity. Hepatitis A vaccine is recommended for some foreign destinations, particularly outside Europe and North America. There are hepatitis A vaccines for both children and adults.

Childhood

For maximum protection against infectious disease, vaccination should be given early in life. It is often therefore the first 'invasive' medical procedure that a child with haemophilia and their parents will face. There has in the past been a lot of anxiety from parents and general practitioners of haemophilic children about the risk of bleeding associated with injected vaccines and this has led to unnecessary delays in implementing normal childhood vaccination programs. Education of parents and liaison between Haemophilia Centres and primary health care teams have helped resolve this and has promoted the message that haemophilia or any other bleeding disorder is not in itself a reason to delay or prevent vaccination. The only significant deviation from normal practice is the delivery of the vaccine where possible by subcutaneous or intradermal routes rather than intramuscular. Other important factors which could modify vaccination schedules include HIV infection in either the individual to be vaccinated or a close family contact (see below) or a predisposition to allergy. These issues should be raised in pre-vaccination discussion.

In the absence of relevant medical problems each child with haemophilia or similar bleeding disorder should have received the following vaccines:-

By 6 months: 3 doses of - DTP
(Diphtheria, Tetanus &
Whooping cough)
- Hib (haemophilus b)
- polio
- hepatitis B

By 15 months:
MMR (measles/mumps/rubella)

By school entry:
4th DTP and polio;
MMR if missed earlier

Between 10-14 years
BCG (against TB); rubella for
girls (if missed MMR)

Before leaving school:
5th polio, diphtheria
and tetanus (DTP)

Adults

Non-immune women:
rubella

Unimmunized individuals:
polio, tetanus, hepatitis A*

* depends on local policy

Foreign Travel

It is very important to plan properly for exotic foreign trips. Get as much detailed information about all places to be visited and contact your local Haemophilia Centre or travel advice Centre (there should be one in a local health centre). They will give you the necessary advice on which vaccinations are advisable and when they need to be given. They will also be useful sources of information on other precautions such as anti-malarial treatment. Again, where possible (and this often is), vaccines should be given by the subcutaneous or intradermal route. If you or any of your travelling party are HIV-positive you should inform the person offering advice on vaccination.

HIV positive individuals

There are relatively few but important restrictions on the use of live vaccines in individuals who are HIV-positive. Most recommendations are for those who are clearly immunosuppressed but it is probably wise for all HIV-positive people to follow the same guidelines.

Where appropriate, all HIV-positive individuals may receive routine vaccinations including the live vaccines measles, mumps and rubella. There are however some vaccines which should not be given:-

Polio - the common polio vaccine uses a live virus and is given as a drop of liquid on the tongue or on a sugar lump. This type of vaccine should not be used for HIV-positive individuals or their close family contacts. Instead, the inactivated polio vaccine (IPV) should be used. This is given by injection.

BCG - this is the vaccine against tuberculosis and should not be used in HIV-positive individuals.

Yellow Fever - vaccination against this virus is a condition of entry for some foreign countries. This vaccine should not be used in immunosuppressed subjects. A letter of exemption should be obtained from your Haemophilia Centre.

If you have the slightest doubt about your vaccination requirements or advice you have been given, check with your local Haemophilia Centre. It is also wise to update your information as recommendations do change with the availability of new information and new vaccines.

GENETICALLY-ENGINEERED FACTOR IX

by Dr Paul Giangrande, Oxford Haemophilia Centre

Over the last ten years or so, advances in genetic engineering have permitted the production of a number of human proteins in cultured animal or bacterial cells. The first such example was a genetically-engineered ("recombinant") form of insulin, first introduced in 1982 and now used by many diabetics in developed countries. The isolation of the human gene encoding factor VIII in 1984 led to the development of genetically engineered factor VIII for clinical use in people with haemophilia A ten years later. The theoretical advantages of genetically-engineered products are freedom from the risk of transmission of human viral disorders and the promise of unlimited supplies.

A genetically-engineered form of factor IX has now been produced by Genetics Institute in the United States, and is undergoing clinical trials in several centres in Europe and the United States.

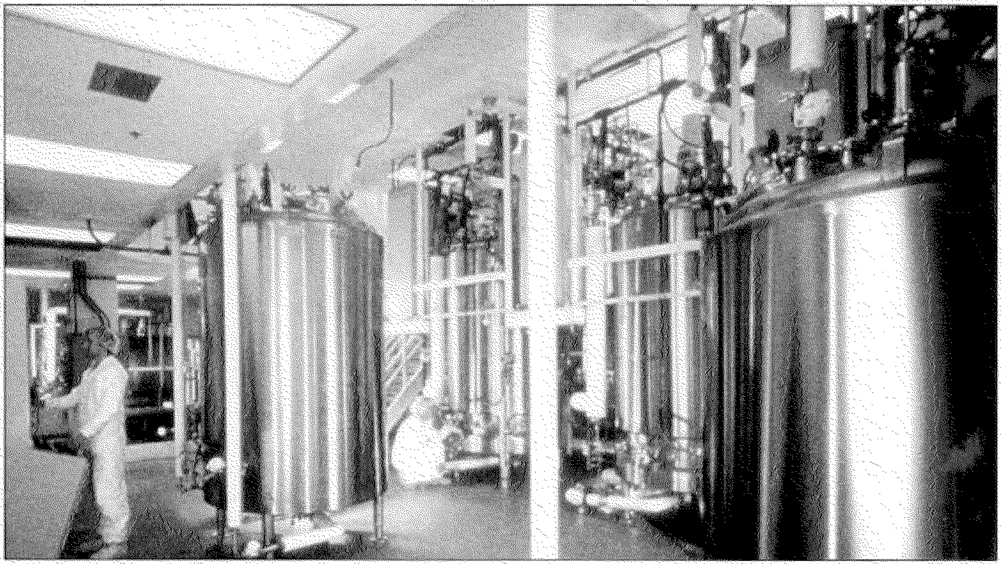
The principles involved in the manufacture of genetically engineered factor IX are much the same as with the equivalent factor VIII products. The human factor IX gene is located on the X-chromosome, one of 23 paired chromosomes in each human cell. Research workers at Genetics Institute succeeded in introducing the human gene into an animal cell, derived from hamster kidneys. These individual cells can live and multiply quite happily if they are grown in a liquid medium kept at 37°C and fed with appropriate nutrients, and they secrete factor IX into the liquid in which they are growing. The picture shows the large steel vats inside the Genetics Institute plant just outside Boston in which the cells are cultivated.

The whole process is a bit like brewing, with live yeast cells kept alive in large vats. In the final process, the factor IX secreted by the cells in the containers has to be extracted from the fluid medium. This is achieved by chromatography with monoclonal antibodies, in which the fluid is drained out of the vats and passed down columns which bind only the factor IX but let everything else pass through.

The resulting liquid is rich in factor IX, but contains no other proteins in significant quantities. Extensive chemical studies have confirmed that the factor IX secreted by the hamster kidney cells containing the human gene is identical in every way to the natural human protein.

The liquid is then freeze-dried, so that the factor IX is turned into a white powder form so familiar to people with haemophilia. This can then be made up with water and injected in the usual way. It is somewhat ironic that all the various licensed preparations of genetically-engineered factor VIII that some patients with haemophilia A use actually contain a lot of human plasma-derived albumin. This has to be added to the final preparation in order to stabilise the factor VIII, which would not last very long on the shelf without a stabiliser.

By contrast, factor IX appears to be a much more stable molecule, and does not require the addition of albumin or any other similar product as a stabiliser. The complete lack of any human protein in the final product implies an even greater margin of safety as regards risk of transmission of human viral infections.



After testing in animals, studies in people with haemophilia B (Christmas disease) were initiated at the beginning of 1990 to compare the half-life (a measure of how long the infused factor IX lasts in the circulation) of the genetically-engineered product with the usual plasma-derived factor IX. These proved to be identical. The product is currently under evaluation in the setting of surgery, to ensure that bleeding is controlled just as well as would be expected with conventional factor IX concentrates. The next step, as is usual in such research programmes, will be to give the genetically-engineered factor IX to a limited number of young children and others with haemophilia B (Christmas disease) who have received no blood products before. These patients will use the recombinant product just like normal concentrate, either as prophylaxis or to treat bleeding episodes, and will be followed up regularly over a period of many months. It will, for example, be very important to monitor the incidence of development of inhibitors in people with haemophilia B receiving this new product. Extensive clinical testing and data analysis inevitably takes a few years, but the company hopes that recombinant factor IX will be licensed for clinical use in the United Kingdom by the end of 1997.

There are approximately 1,100 people known to have haemophilia B (Christmas disease) in the United Kingdom. Most of these already receive a high-purity, plasma-derived factor IX concentrate rather than the intermediate-purity equivalent. The extent to which genetically-engineered factor IX will eventually be used in this country will depend on many factors. Inevitably, cost will be one such factor. Genetically engineered factor VIII costs more than twice as much as intermediate-purity factor VIII. This gap in price has been widened by the recent imposition of VAT at 17. 5% on recombinant factor VIII. An increasing number of products for the treatment of people with haemophilia and related disorders will now be taxed in this way, including the several brands of recombinant factor VIII now available, recombinant factor IX as well as porcine factor VIII and recombinant factor VIIa for the treatment of those with inhibitory antibodies.

Footnote: Those with an interest in computers and access to the Internet can seek more information about recombinant factor IX on the Genetics Institute web page on http://www.genetics.com

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SOUTHERN AND HAMPSHIRE TRIPS TO BPL

by Southern Group Vice Chairman Richard Haynes

GRO-D

Following interest at our AGM last year and the concern about the safety of blood products, the Southern Group arranged a visit to BPL with the aim of allowing local families living with haemophilia and local medical staff to see for themselves the conditions under which the factor products are made.

It also aimed to give them the chance to ask questions of the staff about what they saw, any concerns they have over the products and what is happening in the future. I saw the visit as being therapeutic both from what they saw and heard and from having a social day out together.

In the event 32 members of both the Southern and Hampshire groups and a few staff of the Bournemouth Haemophilia Centre made the visit.

The weather was really hot and sunny so there was much relief as we donned our white protective barrier spacesuits and toured the factory with its temperature resembling winter rather than summer. The trip was fascinating and our admiration for these staff who had to work in these conditions gave a new respect for that little bottle of protein that we so much depend upon.

Everyone was amazed, if not a little green, with videos and photographs of the raw plasma which resembled greenish tripe.

We had a guided tour following the route of the plasma processing through to the 8Y and 8SM production areas (although not into the inner sterile rooms) and bottling rooms.

After the tour, members of the staff gave us two very informative talks relating to the manufacturing process and issues of safety. This was followed by an open discussion time, when many questions were asked and answered.

As our visit was on a Saturday the plant was not actually producing anything, which gave us the freedom to tour it, but a handful of staff gave up their Saturday to host the visit. BPL had provided a wonderful buffet and the children (all right, all of us) were given goodies as souvenirs of the day.

All who attended said how beneficial it had been, and BPL were very pleased to host and hear the views of the ultimate end users of their blood products (evidently for the first time).

I feel that it was fascinating from start to finish and it had, in more than one way, improved the understanding of both suppliers and users. This must be to the benefit of all people affected by haemophilia locally and nationally. BPL indicated that they would welcome more such visits from any of the Society's groups.

THE EUROPEAN HAEMOPHILIA CONSORTIUM MEETING

Each year, all the haemophilia societies in Europe get together at the annual meeting of the European Haemophilia Consortium (EHC). This year, for the first time, the UK Haemophilia Society hosted this meeting in October at the Novotel, near Heathrow, and by common consent it was a great success.

This is a great opportunity to share experiences in the legislative fields, new developments in treatments and products, campaigns and just to share good ideas with each other. Over 90 people attended this year's meeting from 27 countries, from Israel in the South, Russia in the East, Sweden in the North and Ireland in the West. These meetings are particularly useful for those delegates from the former eastern bloc, where treatment provision is still very poor or non-existent. This meeting gives them the chance to meet haemophilia treaters and others who have had to deal with similar problems to the ones they are facing.

The meeting ran from Friday night to Sunday lunchtime with a very full schedule of presentations and discussions, on such topics as prophylaxis and continuous infusion, parvo virus and Creutzfeld Jacob Disease, product safety, and employment and haemophilia. On the Friday afternoon we organised a visit for some of the delegates to the Haemophilia Centre at St Thomas' Hospital, where one of the delegates from Albania was able to receive some much needed treatment. Our grateful thanks to all at the centre for their help!

It was not all work however. At the Saturday night dinner, the delegates were entertained by the "Stockyard Stompers" a 20s style Jazz band, and on the Sunday after the meeting finished, we arranged a sightseeing trip around central London. There is no doubt that the meeting was of great benefit to all the countries who attended, as well as being enjoyable, if hard, work.

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CONSTITUTIONAL CHANGES

During 1995 members of the Executive Committee and Council have been working on a new constitution for the Society.

A new Memorandum and Articles of Association have been prepared to set the legal framework for the management of the Society. These will be presented to members for approval at an Extraordinary General Meeting to be held on 2 March 1996.

In addition a new set of Notes for Guidance for Groups will come into effect and amongst other things will officially recognise special interest groups (eg for HIV and hepatitis) as well as our traditional geographical groups.

The new constitution brings the Society up to date in meeting modern Company and Charity laws. The Charity Commission exercises tighter supervision over charities these days. We must also be able to demonstrate that we meet the highest standards of conduct and public accountability and our new constitution will help us to do this.

Many of the changes are "technical", but some affect all members noticeably. For example - the Executive Committee will be known as "Trustees", will be 11 in number, and will be elected by postal ballot. Postal voting will allow every member to participate in the election. The Trustees will continue to have full responsibility for the Society's affairs. To keep membership up to date a new form will be issued to new and renewing members in a few week's time. Please do return this - it's the only way you'll be sure of a vote in the elections! An increase in membership subscription has also been agreed. The fee will now be £10 per annum with a reduced rate of £5 for other members at the same address. In cases of hardship the fee will continue to be waived - but we still need a completed membership form.

Details of other changes will be published in future editions of the Bulletin and we hope you will agree that they will keep the Society a democratic and dynamic organisation!

HEPATITIS MEETINGS

The format of the hepatitis meetings that have been held in various locations throughout the country has proved to be very successful.

Five meetings were held in 1995: Cardiff, Liverpool, Glasgow, Belfast and London, the most recent being at London on November 11. The first four meetings were all held in the evening. They comprised a presentation from a liver specialist on hepatitis C, followed by an hour of questions from the audience and a buffet supper and the chance to get together and discuss the presentation.

Between 60 and 90 people attended the meetings and the feedback received via the evaluation forms has proved to be very positive.

The fifth meeting, which was held in London, was held on a Saturday and was a full day event. It covered an overview of the future of haemophilia care by Dr Mary Cahill from the Royal London Hospital and included hepatitis from the perspective of haemophilia consultant Dr Chris Ludlam of the Royal Infirmary of Edinburgh and from liver specialist Dr Voi Shim Wong of Addenbrookes Hospital in Cambridge. Special thanks are due to Dr Wong for stepping in at very short notice.

"All of the meetings have highlighted the fact that there is still a very great need for information about hepatitis C," commented Haemophilia Society Director of Services Graham Barker. "We will be looking at the format for further meetings in 1996 and would welcome people's views on whether they prefer meetings held on weekday evenings."

The Society would like to thank all of the clinicians who spoke at the meetings, and also give special thanks to Bayer plc who have supported the meetings.

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HEPATITIS C BOOKLET

People wanting to know more about hepatitis C should remember that the Society has an information booklet available on the subject. If you would like a copy please call Tom Bradley at the national office.

MANOR HOUSE GROUP

The Manor House Group now has a PO Box for correspondence. People wishing to contact the Manor House Group should write to: The Manor House Group, PO Box 128, Nantwich CW5 8PQ.

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TRADITIONAL CHINESE MEDICINE

My name is John Tindall, I am the manager and Chinese Medicine Specialist for the Gateway Clinic in London. This article is an initial attempt to help you have a basic idea of how Traditional Chinese Medicine views the human body and the treatment of hepatitis C.

We provide treatment for 50 clients each day. General health and hepatitis C clients require a GP referral. Our success with hepatitis C is only hearsay evidence as a result of our observation, however, further follow-ups are being carried out. 55% of our clients do show a marked improvement in their health profiles.

Principles of Traditional Chinese Medicine

The ancient Chinese observed that all life required energy (which they called the 'Qi') in order to function correctly and that provided this 'Qi' was balanced and flowing properly the body would have excellent health. To describe how the Qi presents itself the terms Yin and Yang were used. The nature of the Yin is: cool, moist, calm, deep, nourishing, similar in quality to blood. The nature of the Yang is: warm, dry, active, superficial, protective, similar in quality to the energy circulation of the blood. The balance of these two functions within the body creates an essential harmony. Internal organs belong either to the yin or the yang, which form part of the five elements of which our body is made up, reflecting the cycle of nature. The cycle of these five elements is as follows: Fire (connected to the heart and small intestine), Earth (stomach and spleen), Metal (lung and colon), Water (kidney and bladder) and Wood (liver and gall bladder).

The function of the liver within the Yin and Yang is as follows:

Yin Nature: to store blood, to nourish the eyes, to lubricate the tendons and ligaments, to provide blood to the body as and when necessary. It is manifested in the nails. Yin energy can be maintained by a life style that will nurture the Yin qualities of the body ie sleep, relaxation, diet, exercise, rest etc.

Yang Nature: to smoothly circulate the energy and consequently the blood throughout the body (Qi moves the blood and blood nourishes the Qi).

If the above two functions fail there are far reaching consequences throughout the body. If the liver Qi stagnates this is rather like the turbines of an engine getting stuck, which creates heat and consumption of lubricants and the build up of toxic material. If this occurs it causes pain, internal heat, sweats and fevers, cold extremities, digestive disturbance - nausea, vomiting, abdominal bloating, bitter taste in the mouth, loose or incomplete stool, constipation, jaundice, PMT, dysmenorrhoea, head-aches, dizziness, anger, irritability etc.

If the Yin of the liver is damaged by liver Qi stagnation, the body will begin to dry out and harden and cease to function. This is a similar picture to cirrhosis and cancer of the liver from a traditional Chinese medicine perspective.

The art of Chinese medicine is to make a very accurate individual diagnosis and then carefully extract the element producing the disease from the body and at the same time restore the internal strength and balance. The result of this for the client is that they may become symptom free and feel strong and healthy again. The rate and degree of success will depend on how far down the line of illness the client has travelled and how willing and persistent they are to change and maintain a healthy life style. Having said this, all clients will find traditional Chinese medicine helpful to some degree.

From my experience Chinese herbal medicine is essential to return the liver function to normal and inhibit the hepatitis C viral activity, soften the liver and help control/inhibit cancer. The use of herbs has received a very bad press in recent times and yet if the prescription is very carefully thought out and the doses of each herb kept to the most appropriate level for each client then great results are obtained quickly. Chinese herbs and dietary therapy can be used with all clients even in the late stages of the disease to improve the quality of life without causing any further damage or side effects.

Any client with hepatitis C wishing to use Chinese medicine must consult a registered practitioner who has a working experience of their condition, and should keep their GP or consultant informed of their progress.

For more information or advice you can contact the Register for Traditional Chinese Medicine on: GRO-C They will provide names of registered practitioners. Or contact John Tindall at the Gateway Clinic on GRO-C for further advice.

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THE THANKSGIVING SERVICE – A REFLECTION

On Saturday 28th October 1995 I attended the Society's annual service at St Botolph's without Bishopgate in London. I was there, not as a grieving parent, partner, carer or medic but as one who had lost many colleagues over the year.

I am a person with haemophilia aged 47 and attend one of the nation's largest centres ... I have been a patient there for over 30 years ... over that period of time I had got to know many of the other patients very well. In those days, before home treatment, one spent many days, weeks or even months side by side with other people with haemophilia on the wards. When you are next to someone all day and talk to them for hours on end you get to know them very well indeed. Unlike many other illnesses, with haemophilia, hospitalisation is not a one off episode, but a life long relationship with medics and other patients.

Then, come the 1980s, you realise that due to HIV there are not so many around of those that you had known for all those many years ... and then less and less. Why am I still here and they are not?

So that is why I was at St Botolph's that autumn afternoon, to try and answer that question. Yes, I had been to other services in the past, but some years it seemed too much to cope with.

We are all very fortunate in our Chairman, the Rev Prebendary Alan Tanner - his faith, perception and sincerity at that service was a comfort to me and I am sure to everyone present. The hymns, readings and anthem were uplifting. To me it helped to remember those who are no longer with us and to explain why.

A particularly poignant part of the service was when everyone was invited to write names, messages and personal thoughts on cards provided and place these, in confidence, in a basket on the altar.

As time moves on I find myself writing a longer list each year - 1995 saw 10 names on my card.

If you have never been to the annual service and hesitate because you think that it is not for you, that it will be morbid and distressing, please believe me it does help explain your fears, anxieties and questions ...

An extract from the reading, for me sums it all up:

"I have seen death too often to believe in death.
"It is not an ending but a withdrawal."

If we hang on to that then there is hope ...

GRO-A

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BAXTER CONFERENCE

Baxter Healthcare recently held a conference in London entitled "Recombinant factor VIII - current and future perspectives".

The day-long conference covered such areas as safety, prophylaxis, the cost benefits of continuous infusion, clinical trial experience and the economic justification for the use of recombinant products.

The speakers included eminent doctors from the haemophilia world, such as Dr Eric Berntorp, Dr Martinowitz and Professor Harold Roberts.

Baxter Healthcare currently have a recombinant factor VIII product, Recombinate, on the market which is now being used in the UK.

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