ISSN: 1357 - 5171

The Bulletin

1995 – No 2

HAEMOPHILIA RESOURCE PACK NOW AVAILABLE

A new haemophilia resource pack is now available for parents of children newly diagnosed with haemophilia.

The packs, which include everything that you would need to know about haemophilia, have been produced by Bayer in cooperation with the Haemophilia Society. They will be given out at centres to new parents of children with haemophilia.

The resource packs are very user-friendly and include quotes from parents who are already living with a child with haemophilia. The information in the binders is very comprehensive, covering the subject right through from the causes of haemophilia to routine diagnosis and care, treatment and growing up with haemophilia. They come in the form of a loose leaf binder so that individual pages can be photocopied and handed out to relatives, teachers or child minders who need to know more about haemophilia.

Graham Barker, Director of Services for the Society commented on the new resource packs: "One of the most stressful times for families is when they discover that they have a child with haemophilia. The new packs provide detailed and easy-to-understand information about the condition at the time when families need it most. We are very grateful to Bayer and Maxim Medical for producing the packs, which are a significant step forward in helping the families of newly diagnosed children with haemophilia."

GRO-D

The first pack was presented recently at Great Ormond Street Hospital for Children NHS Trust to new parents GRO-D and their 3 month old son GRO-D Pictured with the GRO-D from the left at the presentation are: Haemophilia Nurse Specialist Kate Khair, Deborah Williams of Bayer and Graham Barker (right).

HEPATITIS C CAMPAIGN UPDATE

There have been a number of developments in the hepatitis C campaign since the last edition of the Bulletin.

An all-party meeting of MPs was held at the House of Commons 26 April, jointly chaired by MPs Sir Geoffrey Johnson Smith (conservative) and Alf Morris (labour). Around 20 MPs attended the meeting and were very supportive of the Society's position.

As a result of this an Early Day Motion (number 1219) has now been put down in the House calling for the Government to recognise the plight of people with haemophilia infected with hepatitis C, and to consider providing help in a similar way to that already given to people who are HIV positive. Currently 191 MPs of all parties, have put their names to the Motion and it is hoped that more will come on board in future. The more support shown by members of parliament, the more likely it is that the Government will take action.

This is where Society members can be very useful. If you haven't yet written to your MP about hepatitis C, please do so. If MPs know that hepatitis C is a problem that is affecting their constituency then they are more likely to support the campaign and sign the Early Day Motion.

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Editor of The Bulletin
Andy Cowe

EDITORIAL by Bulletin editor Andy Cowe

A glance through this edition of the Bulletin gives an instant picture of the work of the Haemophilia Society. Regular readers will notice two new features. Service Shorts will keep readers informed about aspects of our work which sometimes go on unseen but are the heart of our service to members. The Red Ribbon page will reflect our activities and support for people with haemophilia and HIV.

The articles on the hepatitis C campaign and liver biopsy show our concern over hepatitis. News of staff changes and the column from the Manor House Group demonstrate some of our responses to this threat.

We also have a number of good news stories. Our AGM report highlights this year's awards to people with haemophilia who have achieved excellence in education, music and sport. The stories about GRO-A and GRO-A show that haemophilia, when properly treated, need not be a bar to a full and active life.

Letting parents know that haemophilia can be overcome is one of the most important jobs this Society can do. We bring news of a range of parent's support activities and publications which can help. The launch of the Haemophilia Resource Pack (our headline story) adds to the resources we have at hand to achieve our objective – improving the quality of life for people with haemophilia and their families.

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
- Hepatitis
- The Essentials of Haemophilia Care
- Teaching Children with Bleeding Disorders
- 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:

- Support to children and families affected by HIV and haemophilia
- 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.

In this issue

HEPATITIS WORKER APPOINTED

The Society has appointed a hepatitis research worker on a six month contract to explore the needs of people with haemophilia and hepatitis C.

Mandy Cheetham started work at the Society on June 7. She will be based at the Society national office, but will also travel to Centres up and down the country. She will be interviewing people with haemophilia and hepatitis C, their families and health care professionals about the implications of the virus.

She will also be monitoring the services offered by Haemophilia Centres to see how closely they comply with the UK Haemophilia Centre Directors' Organisation Guidelines.

Mandy is a qualified social worker and joins the Society from the St Giles Trust, where she was working with homeless and vulnerable people in London. In this work she has encountered many people who are HCV positive.

"I will be investigating the special problems that the combination of haemophilia and HCV cause," she said. "My job will involve talking to as many people as possible in the six month period to find this out. If people have difficulties or experiences they would like to share about how the virus has affected them they are very welcome to call me at the Society national office in complete confidence."

NEW INFORMATION AND ADVICE WORKER POST

Shanit Marshall has been appointed to the new post of Information and Advice worker at the national office.

The new post has been created to ensure that people with haemophilia and their families have someone to come to for advice and information about haemophilia and benefits.

"I was very pleased to have the opportunity to take on this new role," said Shanit. "The job is very wide ranging and will be far more challenging than my previous post of clerk to the services department."

Shanit will be the first port of call for people with haemophilia wanting advice on subjects such as: treatment, HIV, HCV, mortgages, insurance and benefits.

She is also responsible for providing literature, research for publications and advice sheets in addition to working on the administration of financial assistance grants, organising conferences and liaising with other organisations.

NEW CENTRE DIRECTOR FOR LIVERPOOL

NOT RELEVANT

Dr Toh is pictured with Julien.

The new Director for the Haemophilia Centre at the Royal Liverpool and Broadgreen University Hospitals NHS Trust took up his post in March.

Dr Cheng Hock Toh graduated with honours from the University of Sheffield in 1985, and brings to Liverpool his clinical and research experience from both Sheffield and Queens University, Ontario, Canada. His wife, Christine, has also been involved in haemophilia research, and her interests have been in the molecular biology of hepatitis C. Her time is now spent fully employed in looking after their first child, Julien, who arrived exactly one month after their move to Liverpool.

Dr Toh, who is also Senior Lecturer in Haematology at the hospital, says that for the future of the Centre there is "an emphasis on the multidisciplinary approach which has incorporated not only the skills of a new Professor in Orthopaedics, Simon Frostic, but also that of a Consultant Hepatologist, Dr Ian Gilmore and Consultant Virologist, Dr William Tong."

SARA PARTRIDGE 1959-1995

Sara Partridge, who worked at the Oxford Haemophilia Centre, died in a tragic accident recently. Oxford Centre Director Dr Paul Giangrande sent the Bulletin this tribute.

Sara was a Clinical Nurse Specialist here at the Oxford Haemophilia Centre. She was killed in a diving accident off Swanage in Dorset on Sunday May 14th. Her death represents a tragic loss to patients and staff of the Oxford Haemophilia Centre. Sara was [illegible] Years old and qualified as a nurse at the Middlesex Hospital in 1981. She subsequently worked in a number of London Hospitals as well as in a general practice for some years before settling for a career in haemophilia care. She worked as a Sister in the Haemophilia Centre at the Royal Free Hospital between 1989 and 1992. I knew Sara well from my own days at the Royal Free Hospital, and I was delighted that she joined us at the Oxford Haemophilia Centre as a Clinical Nurse Specialist in 1992. She was enthusiastic in her work, with a warm and outgoing personality. She was keen for the role of nurses in haemophilia care to expand and develop and was instrumental in making significant changes in the running of our Centre. She was particularly involved in the treatment of young children with haemophilia. She was active at national level in the Haemophilia Nurses Association and other organisations. Indeed, Sara and myself were scheduled to give a joint presentation on hepatitis in haemophilia at a meeting of nurses at Hammersmith Hospital this June.

She will be sadly missed by us all at the Oxford Haemophilia Centre.

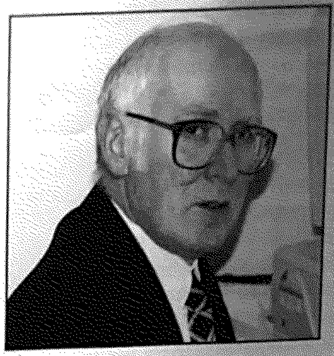
A PROFILE OF PHILIP DOLAN

Philip Dolan was elected onto the Executive Committee of the Society at the AGM in May of this year. He is a staunch supporter of local groups and believes that great emphasis should be placed on the provision of uniformly high standards of care in the treatment of haemophilia.

Philip has haemophilia A and has been a member of the Society for about 30 years. For the last 20 years he has been an active member of the Scottish Groups. He has been chairman of the West of Scotland Group for the last eight years.

"One big issue for the group has been to improve the standard of the accommodation for people with haemophilia at the Glasgow Royal Infirmary," he said. "We have made some progress on this, but there is still more that needs to be done.

"We've also had a successful dialogue with the Scottish office on the need to have a circular on Comprehensive Haemophilia Centres, as had already been produced in England and Northern Ireland.



Philip Dolan

"Another issue we've been involved in is the provision of interferon treatment. There was a move for it to be prescribed by GPs instead of the hospital in Glasgow. This could potentially have caused problems for people in gaining access to treatment. We spoke to the Chief Medical Officer in Glasgow, and now interferon is available from the Glasgow Royal Infirmary."

Philip is quite experienced in dealing with issues around the quality of care. For 10 years he was a member and subsequent chairman of the Hamilton and East Kilbride local Health Council. He is also a member of the disability appeal tribunal representing the interests of disabled people.

He started his working life in the printing industry, but had a career change when he was in his twenties and studied social work at the Universities of Glasgow and Hull. "My social work background can be quite useful in my work for the Society as I can help with information about benefits and counselling," he said. For the past 20 years he has been area manager for Strathclyde, responsible for the social work services for a population of 120,000 people.

Now that he is on the Executive Committee he has three prime areas of interest. Strengthening local groups, which he sees as the backbone of the Society. Hepatitis C - which he sees as becoming an even greater cause for concern as time goes on, and the quality of haemophilia care, which he believes should be uniformly high throughout the country and sensitive to the needs of those treated.

His hobbies are photography, wine tasting and travel - he likes to make spur of the moment trips to exotic locations. He has a wife and 12 year old son.

LIVER BIOPSIES

By Dr Chris Ludlam

Centre Director, The Royal Infirmary of Edinburgh

The procedure for obtaining a small sample, or biopsy of the liver is a well established technique that has been used for many years. Most biopsies are performed by first anaesthetising a small area of skin over the liver in the upper part of the abdomen and then passing a special biopsy needle through the skin into the liver. On withdrawing the needle a small piece of liver about 1-2mm in diameter and perhaps 10mm long is retained within it. This is sent to the pathology department where it is processed and examined under the microscope.

There are many disorders that can affect the liver and some of these can be diagnosed by specific blood test, e.g. different forms of viral hepatitis, but sometimes this is not possible and a biopsy is suggested. In the case of hepatitis C infection this can be diagnosed by a simple virological blood test. The blood "liver function tests" sometimes provide a measure of its inflammation but they do not reflect how severely it is affected by a disease process. Neither of these blood investigations, however, reveal the extent to which the liver is damaged by cirrhosis or scarring. One way in which this can be measured is by performing a liver biopsy. As well as revealing the extent of scarring, under the microscope, it is also possible to visualise the degree of inflammation. If there is any doubt about the cause of a liver problem then a biopsy may help the diagnosis.

Thus in individuals with hepatitis C infection it provides information about the degree of liver damage as this may be considered important by some doctors in helping to decide whether interferon should be offered. In people without haemophilia a liver biopsy is considered advisable by many doctors before prescribing interferon. In those with haemophilia who have hepatitis C it is not a prerequisite to interferon therapy. Many doctors will offer interferon to those with haemophilia without a biopsy.

Is a biopsy safe? Liver biopsies 10 to 20 years ago were associated with more side effects. Biopsies today are performed using safer needles and are usually undertaken with the help of ultrasound which can visualise the liver on television screen thus ensuring that the doctor can guide the needle into the liver. Some centres use a laparoscope which is a tiny telescope which can be inserted through a small incision in the abdominal wall and can be used to visualise the liver to ensure that the biopsy needle enters it safely. Using a laparoscope it is also possible to see the degree of inflammation and cirrhosis.

Before a biopsy it is necessary to give factor VIII or IX concentrate to raise the level. After the biopsy this should be continued with further infusions for about 3 days. A biopsy would not normally be performed in an individual with an inhibitor because it would be harder to raise the factor VIII or IX level to prevent bleeding. There is a small risk of bleeding after a biopsy and this may need to be treated by a blood transfusion. Very occasionally the bleeding will be problematic and an operation will be required.

If your doctor suggests that you have a liver biopsy you should ensure that you receive a full explanation as to why it is considered necessary and exactly how it will be performed. With this information you should be able to make a decision that is reasonable for your circumstances.

NOT RELEVANT

THE ANNUAL GENERAL MEETING

This year's Annual general Meeting of the Haemophilia Society was held at the Prideaux Theatre, St Thomas' Hospital on Saturday 13 May.

The meeting was opened by the Chairman, the Rev Preb Alan Tanner with a moment's silence to remember those who had died in the past year.

The Chairman said that the Annual Report largely covered a year of consolidation for the Society after a large number of significant changes last year. He said that all concerned should be congratulated that all difficulties had been resolved.

Two special reports were made to the meeting - one on the constitutional review, and one on the hepatitis C campaign.

CONSTITUTIONAL REVIEW

Andy Cowe spoke on the results of the Constitutional Review of the Society. He reported that the working party had brought a number of reports to Council and received their views, and by April of this year had their broad agreement for a series of recommendations.

Items of interest among the recommendations were:

- The Memorandum of Association objects clause of the Society needs to be updated in line with modern practice and brought before the Charity Commission.
- Executive committee members are to be renamed as Trustees. There should be 11 Trustees, and the term of office should run for two years with no person being able to serve more than three consecutive terms of office.
- The Chairman should have a vote in the meetings instead of the current position of only having a casting vote.
- Postal ballots of members for the election of the Executive committee and officers of the Society should be held instead of members having to attend the AGM in person.
- Members of the Society need to be better defined in the Memorandum and Articles. There should be differentiation between voting members and mailing list members - for example libraries who are on the Society mailing list do not need to have voting rights.

The proposals will be brought before an Extraordinary General Meeting of the Society in November of this year and the new system be running by 1996.

HEPATITIS C CAMPAIGN

Simon Taylor reported on the hepatitis C campaign.

He reported that the Society had been working to ensure that as much information is passed on to members about hepatitis C as quickly as possible. A prime channel for this is the Bulletin. The Society is also producing a new booklet on Hepatitis C.

The campaign itself is going well, but is not as easy as the HIV campaign in the '80s as there is not the same public appeal. He reported that the Society had contacted its friends in Parliament and that Ministers had already received over 150 letters from MPs interested in the situation. There has also been an all party meeting in the House of Commons with supportive MPs. Mr Taylor said that the Society is currently working towards a motion in the House, which would be followed by a meeting with the Minister and then perhaps with the Prime Minister.

ELECTION OF OFFICERS AND EXECUTIVE

The Chairman was elected unopposed, but he took the opportunity to say that he intends to continue in office only for a further two years. He said that this would allow him to see through the HCV campaign and the constitutional review.

The treasurer Nicholas Lawson was re-elected unopposed.

There were three candidates for the post of Vice Chairmen. Standing were Simon Taylor, Chris Hodgson and John Pepper. Elected were Simon Taylor and Chris Hodgson.

For the Executive committee it was reported that Julian Lander and Carol Holliday were standing down. The Chairman thanked both of them for their services to the Society and made particular reference to Julian Lander. He said that Julian had been on the Executive committee for many years and had held almost every office in the Society. He applauded his sustained service to the Society and remarked that it could not have taken place without a considerable cost in Julian's time and energy.

NOT RELEVANT

As there was one vacant seat all of those standing for the Executive committee were elected unopposed.

NOT RELEVANT

They were: Gordon Clarke, Keith Colthorpe, Andy Cowe, Philip Dolan, David Evans, Norma Guy and John Pepper.

The President remains Dame Catherine Cookson OBE.

The Chairman reported that Dr [illegible] Mayne was standing down from the Medical Advisory Panel. He thanked her for the immense amount of service that she had given to the Society over the years and to himself personally. Dr Paula Bolton Maggs was elected to the panel in her place. The other members of the medical advisory panel remain unchanged.

The Chairman then thanked all those people who have helped the Society. He singled out those people who served on the local Groups and committees, the executive committee and vice presidents and Society staff. He also thanked those parliamentarians who have given support and paid especial thanks to the Society patron the Duchess of Kent GCVO.

NOT RELEVANT

NOT RELEVANT

The afternoon session was taken up by an informative talk from Dr Mark Winter from the Canterbury Haemophilia Centre on prophylaxis and recombinant factor VIII products.

Speaking on prophylaxis, he pointed out that it was a well-established form of treatment that was aimed at keeping the level of factor VIII or IX in blood above 1%, so as to prevent any episodes of spontaneous bleeding. He stressed the benefits of this form of treatment, particularly for children, as it can prevent damage to the joints.

NOT RELEVANT

Once a joint has actually been damaged by bleeding, the most that prophylaxis could achieve was to prevent any further deterioration in the affected joint.

He also pointed out that prophylaxis is not only for children, but is frequently used for adults, such as when surgery is being performed or when the person experiences a series of bleeds into one particular joint.

He also made the point that prophylaxis does not necessarily need to be continuous but that it is tailor made to the needs of each patient with haemophilia. He gave the example of a child who tended to bleed in the summer holidays, but not when at school. Under these circumstances, Dr Winter said that he would treat the child prophylactically at the time when the bleeds were occurring - during the holidays - but would not use prophylaxis during term time.

He also discussed the issue of portacaths, which are used in some centres to gain venous access for very small children with haemophilia. He said that in his experience it was usually possible to gain access to even a very small vein by conventional means, particularly as it was often possible to make the vein larger by warming the patient's hands in a bowl of hot water. Furthermore, veins tended to get bigger the more that they were used. He tended to use portacaths only as a last resort when venous access by any other means was not possible.

He reminded members of the Society that as a patient group they had a great deal of political power and had the ability to influence the way in which they were receiving treatment. He said that his own local Group in Kent had

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SOCIETY AGM

been instrumental in persuading the commissioning agency that the highest standards of care should be given at all times. It was for this reason as much as any other that all severely affected children under his care were now being treated in a new centre with recombinant factor VIII, used prophylactically.

In the future Dr Winter expected to see better delivery systems for prophylactic treatment with factor VIII. This was likely to involve the use of a continuous infusion pump, attached to the skin which would deliver factor VIII into the vein at a slow and steady rate. This would make the factor VIII more effective and would also reduce the amount of factor VIII that needed to be injected overall.

Concerning recombinant factor VIII, Dr Winter said that he had been using this product in his centre for the past few months. The advantage of recombinant factor VIII is that it is not derived from human plasma although the genetic engineering process does involve the human factor VIII gene.

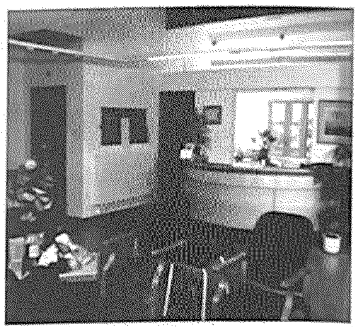
He believed that recombinant factor VIII is a genuine advance for people with haemophilia and that it is likely that in time it would replace factor VIII of plasma origin as the standard treatment for all patients with haemophilia. Although monoclonally purified factor VIII appeared to be safe there remained a theoretical possibility that viruses could be transmitted. The pattern of blood product treatment over the past twenty years had been for a new virus to be discovered every few years. On this ground alone he felt it likely that there might well be other viruses in the plasma supply that we had yet to learn about and that this was a concern for as long as patients with haemophilia were being treated with plasma-derived factor VIII.

In answer to a question from the audience on the relative effects of recombinant, high purity and intermediate purity factor VIII on the immune system he replied that he could not see any strong evidence for there being any significant impact from either recombinant factor VIII or high purity plasma factor VIII on the immune system, as they are both very pure. He commented that the use of intermediate purity factor VIII was no longer formally recommended by the Haemophilia Centre Directors' Organisation.

FACE LIFT FOR OXFORD

The Oxford Haemophilia Centre in Churchill Hospital has been refurbished.

The Centre has been in existence since 1968, and was the first to be opened in the UK. It has now been extended and completely refurbished. The Centre is in a single-storey building and also has separate clinical and laboratory wings. New automatic doors at the entrance have been paid for with money provided by the Haemophilia Society.



The new reception area.

To mark the opening a meeting of 50 doctors involved in the care of people with haemophilia from around the country was held at the Centre in March. Guest speakers included Dr Charles Hay from Manchester who spoke about inhibitors and Professor Louis Aledort from New York who spoke about the benefits of prophylactic therapy.

The Oxford Centre has also recently appointed a new consultant haematologist to start in July. Dr David Keeling is currently a senior registrar at Addenbrookes Hospital in Cambridge. He did his general medical training at St Bartholomew's Hospital and went on to train in general haematology at the Royal Free and London Hospitals before spending three years in research at Middlesex Hospital. He has a particular interest in thrombosis. He is married with three children.

NOT RELEVANT

NEWS FROM THE MANOR HOUSE GROUP

–The MHG give their view on hepatitis C

We are aware that the objectives of the Manor House Group (MHG) may cause some parents with young children to become concerned that they may be drawn into situations that they would prefer not to be as a result of the publicity surrounding our cause. This article may also be upsetting to those of you who have already endured the same pressures as a result of the HIV campaign. We hope however, that if you fit into either of these groups you will understand that MHG's objectives are to give support and to seek recompense for those of us who have hepatitis - particularly hepatitis C (HCV) - and that, of course, is most of us.

MHG hopes to achieve its objectives by working in harmony with the Haemophilia Society and we have been grateful for the support we have obtained. The group fully supports the efforts of the Society in raising awareness and the seeking of compensation in the same way that these were achieved for those with HIV. However, we feel that there are a number of aspects of the hepatitis issue that differ fundamentally from the HIV campaign.

The case for HIV was successful because there was - quite rightly - tremendous public sympathy and support as well as a moral obligation. The Society, in their present campaign, are using the same moral argument, but because HCV is not perceived to be as sensational as HIV, MHG feel that additional arguments need to be developed.

It is our belief that the problem was preventable.

At the time when the contamination of blood supplies took place it is quite true to say that the hepatitis C virus was undetectable and unknown; but the medical profession were aware of the risk of transmitting hepatitis B but nothing was done to prevent it. It is our contention that blood products should have been virally inactivated in order to remove the risk of transmitting hepatitis B at an earlier date. This would have prevented the transmission of hepatitis C as well as hepatitis B.

It is shocking to think that action taken at the right time to prevent an infection risk associated with blood and blood products (hepatitis B), a risk that has been recognised for a very long time, could conceivably have prevented both of the infections (HCV and HIV) that have had such tragic consequences for so many.

Of course, HIV and HCV do have different implications for the patient and HCV is generally not as devastating in the majority of cases as HIV but it does lead in many cases to chronic liver malfunction and it can have noticeable effects from very soon after the initial infection. In the early stages, psychological effects apart, HCV is likely to disrupt the patient's lifestyle. Patients often suffer regular episodes of extreme fatigue which can seriously affect their ability to stay in regular employment and to enjoy happy family and social lives.

For those who are not infected the implications can be hard to grasp - have you ever been told that it is all in your mind? This is the reason, we believe, that the medical profession have, for the large part and for a long time, overlooked the seriousness of liver disease in people with haemophilia and von Willebrand's disease. We are well aware that hepatitis C has caused some people more problems than the haemophilia they have been treated for.

Manor House Group believes that the Government has an obligation to help everyone who has contracted hepatitis C through the use of blood products. It is, once again, a case of not exercising due care in the use of a medical treatment; it is a case of using one without due consideration for its side-effects.

It may be argued, by those who would wish to put up some kind of defence for what has happened, that hepatitis C was an acceptable risk. To us, this must be a totally unacceptable stance for anyone to take. It is surely one that must be rejected out of hand by those who have suffered the consequences of yet another unwanted insult to their bodies. How many of us were consulted before we were prescribed this acceptable risk?

We believe that a risk can only be considered acceptable when there is no alternative course of action available. For people with mild haemophilia, DDAVP - an alternative completely avoiding the use of blood products - was available. In addition had blood products been virally inactivated at an earlier date, and we find it inconceivable that they could not have been, the risk could have been virtually eliminated for many others.

MHG would like to hear your views. Do you agree with those expressed in this article? Please let us know. If you support us it is vital that you tell us because the proof of your support amplifies what we are able to achieve. We would especially like to hear from you if you have begun a legal action.

We can be contacted via the MHG, 5 Redfern Way, Norden, Rochdale, Lancs, OL11 5NZ, or if you leave a message with the Society's London office we will call you back.

HEPATITIS C AND LIFE INSURANCE

The Society was recently invited to give a talk to 70 Chief Medical Officers at a meeting of the Association of British Insurers. Dr David Evans, Executive Committee member and GRO-D attended the meeting. Following further discussions at the meeting, it was agreed that the Society would have the opportunity to view and update the main source of information about haemophilia that the Chief Medical Officers use.

The Society will be drawing up guidelines in conjunction with the ABI that will show what people with haemophilia who are HCV positive should expect from life insurance companies. However, several points have already been established thanks to contact with the ABI. They are as follows:

If an individual who has already taken out a life insurance contract later discovers that they are hepatitis C positive, provided the individual completed the proposal form honestly at the time, that policy is valid no matter what diseases or health impairments the individual has since then contracted.

In the same way, an individual who is suffering from a serious medical condition but whose doctor has not told them about the position, is deemed to have taken out the contract honestly and properly, and will also be covered.

It is only on very rare occasions that a life insurance contract is voided and this can occur if an individual deliberately withholds a particularly serious material fact.

It follows therefore that there is no need for an individual to notify a life insurer of a change of risk, be this a risk of health, occupation or other factors. (NB, different considerations apply with annual contracts such as motoring and household, in these cases there is an obligation by policy holders to notify their insurer if the risk changes).

Appealing against an unsatisfactory decision from an insurance company is possible. The person concerned should ask his doctor to write to the company to ask for the decision to be reviewed.

Specific guidelines for people with haemophilia will be published in the Bulletin. If anyone has any problems with their life insurance policy let GRO-D at the national office know.

SCOTTISH NATIONAL BLOOD TRANSFUSION SERVICE DEVELOPMENTS FOR HAEMOPHILIA CARE

by Dr Perry, Director, SNBTS National Protein Fractionation Centre

Patients with haemophilia in Scotland and Northern Ireland will be pleased to hear that after much debate, consultation, argument and passion we have christened our high purity Factor VIII product. Henceforth it will be known as "Liberate". This is derived from the place of manufacture (Liberton, Edinburgh) and the hope that the product helps to liberate patients and facilitate a relatively free, normal healthy life. Other contenders for the title were H8 and Tartanate! - the latter did enjoy a brief informal existence after its adoption by haemophilia doctors to distinguish SNBTS products from others.

Clinical trials are now well underway with our new high purity Factor IX concentrate. This product has been designed to satisfy all current and anticipated future safety standards and we hope the product will also "liberate" haemophilia B patients. Unhappily "Libernine" does not tend to convey the same message of freedom in health so the search is on for a suitable name for this product too. Hemofix (i.e. Hemo FIX) is the front runner at the moment but other suggestions will be warmly welcomed.

Other products under development by the SNBTS include Fibrin Sealant which may find useful applications in Haemophilia care such as dental extractions - "Glenseal" has been suggested as a possible brand name but the association with double glazing or draught excluders is probably too close for comfort!

NOT RELEVANT

INDUSTRY INJECTS CASH

The pharmaceutical industry has generously contributed towards the cost of this year's Adventure & Sport holidays for young people with haemophilia. Alpha Therapeutic, Bayer, BPL, Immuno and Pharmacia have all pledged sponsorship. Graham Barker, the Society's Director of Services said: "The holidays have enabled hundreds of children to enjoy a wide range of challenging activities over the years." Sponsorship of over £1,600 from the London Marathon will also be used towards the holidays.

NOT RELEVANT

BIRMINGHAM HEPATITIS DAY

Following the success of last year's Hepatitis Days, the Society began this year's Hepatitis Roadshow in Birmingham on Saturday 6th May. The meeting was chaired by Andy Cowe of the Haemophilia Society Executive Committee.

Following helpful suggestions from members who attended last year's meetings, the Society made some improvements on the format of the day.

With the new format we were fortunate enough to have the expertise of both a haemophilia consultant, Dr Mike Makris (Sheffield), and one of the country's leading liver specialists, Dr Geoffrey Dusheiko (Royal Free, London). Both talks were very informative, and the addition of a liver specialist proved successful in ensuring that participants were given a well-rounded and detailed picture.

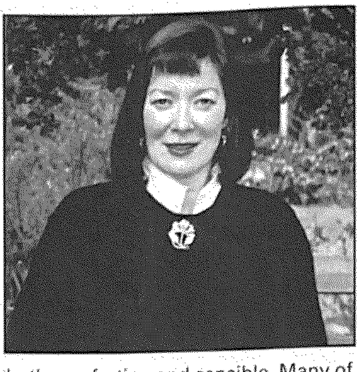
As well as the addition of a liver specialist, the meeting was extended to span a full day. This gave people time to chat over lunch and think of questions they wanted to ask the doctors in the afternoon. The Society also provided a creche for 8 children so that as many parents as possible had the chance to attend the meeting.

The last item of the day was a Hepatitis Campaign update by Graham Barker. This proved to be a vital addition as Graham was inundated with questions!All round it was an extremely successful day, and the best attended Hepatitis Meeting so far, with a turn out of nearly 70!

NOT RELEVANT

A REVIEW OF LITERATURE FOR PARENTS

Vicky Vidler, Nurse Specialist, Haemophilia, from the Roald Dahl Paediatric Haematology Centre in Sheffield reviews publications that are available for parents of children with haemophilia.

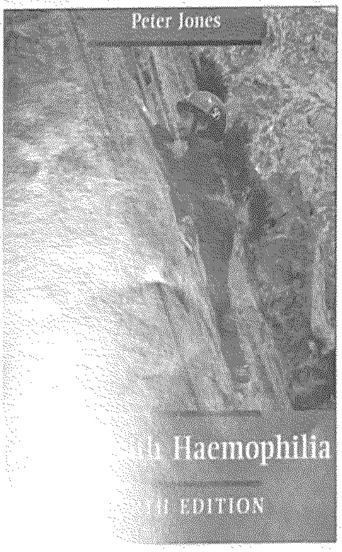


It can be very reassuring to know that when there is something on your mind, a worry that is niggling away at you, that there are a variety of books and leaflets with a wide range of information and guidance to offer. Whilst these cannot take the place of asking questions of your centre staff, they do offer much that can compoiment the knowledge and support gained from the professionals. Please remember that no matter how much you read or how many other families you talk Ito, you know your child better than anybody else, so trust your own instincts!

I would just like to make a few personal comments about some of the books and leaflets you may come across.

LIVING WITH HAEMOPHILIA
by Peter Jones

This book could easily be described as the handbook of haemophilia, written be the much respected and wise centre director from Newcastle, Peter Jones. This book covers a really broad range of subjects. Everything from Queen Victoria's family tree to gene therapy, wisth a great deal in between! The book opens wisth an introduction for new parents which is both comforting and sensible. Many of the emotional issues that accompany life with any chronic condition are dealt with very sympathetically.



The fourth edition of Living with Haemophilia has only just been published and I would wholeheartedly recommend it to you.

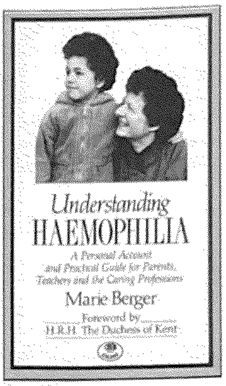
NEW HORIZONS LEAFLETS

These are colourful and easy to read leaflets on subjects such as, sports, being a haemophilia carrier and schools. They are very helpful for giving to such people as school teachers and child minders. Some older children will probably find the information contained in them just at their level.

HAEMOPHILIA SOCIETY BOOKLETS AND THE BULLETIN

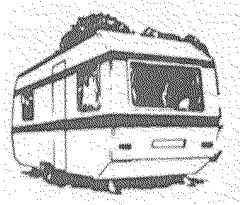
There is a wealth of information contained in the various forms of literature produced by the society. The Bulletin covers the most topical issues of the moment, recently mentioned has been prophylaxis, Port-a-Caths, a hepatitis C update and a questions page. Well worth filing away for future reference!

UNDERSTANDING HAEMOPHILIA
by Marie Berger



Marie Berger writes very openly and honestly in this book about her family's experiences when her son Nathan was diagnosed with severe haemophilia. She freely shares all the conflicting emotions and anxieties that families go through and gives very practical suggestions on how to live with haemophilia. The book contains the historical background of haemophilia and it's treatment in this country. Some families who are new to haemophilia may be alarmed by some of the situations the Berger family have had to face, but those parents who have been living with haemophilia for a while will identify with much in this book.

CARAVAN HOLIDAYS IN 1995



If you are planning your holidays remember that the Society has a number of caravans around the country. The list of caravans and contact people, along with the approximate locations, are listed below:

EAST LOTHIAN Situated at Innerwick, near Dunbar
Mrs Carolyn McGimpsey, 105 Harlawhill Gardens,
Prestonpans , East Lothian EH32 9JH
Tel: (01875) 815223

LANCASTER/MORECAMBE Situated at Caton
Mr Keith Pope, 305 Hulton Lane, Bolton, Lancs BL3 4LF Tel: (01204) 62443

DORSET Situated at Christchurch
Mrs Hughes, 6 Kimberley Way, Western Downs, Stafford
ST17 9QU Tel: (01785) 56012

CAISTER
Mr & Mrs R J Davies 134 Acre Lane Spring Park Northampton
NN2 8DF Tel: (01604) 454217

NORTHERN IRELAND 2 caravans situated at Portrush and Newcastle
Mrs G Shiels, 76 Woodland Park, Kilrea, County Londonderry
BT51 5SA Tel: (012665) 40283