Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392147

ISSN: 1357 - 5171

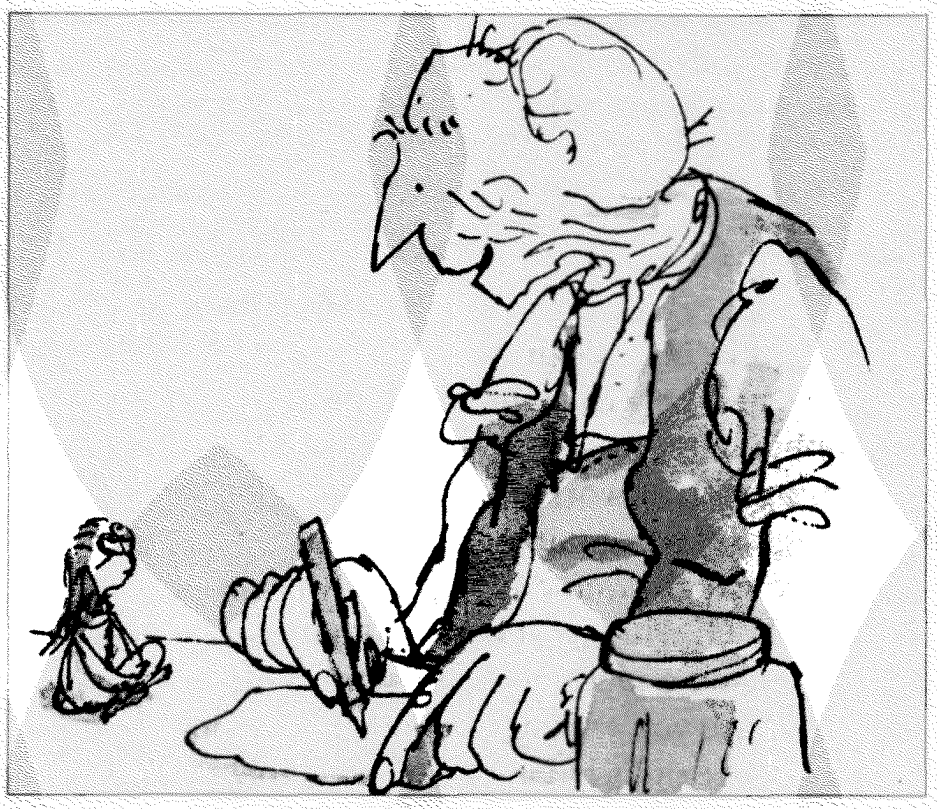
The Bulletin

1995 – No 3

ROALD DAHL FOUNDATION FUNDS CHILDREN & FAMILIES WORKER

The Roald Dahl Foundation has generously agreed to sponsor the costs of a Children and Families Worker. The sponsorship is worth around £50,000 over two years. In order to mark this magnificent donation, the post holder will be known as the Roald Dahl Foundation Children and Families Worker. If you attend a Centre such as Sheffield Children's Hospital, you may have already come across the Roald Dahl Foundation's unit, and, elsewhere, their nurses who very soon will be easily recognised by their badges.

The post will continue and build upon the work of Liz Cox, whose four year secondment from Barnardo's Positive Options ended in June. The emphasis of the work will shift from intensive support for families living mainly in the South East to cover the whole of the UK. We are aiming to achieve this by working closely with Centres to ensure that the whole family is looked after, as well as those members of the family who are receiving treatment for their haemophilia. Many Centres have already expressed positive support. The scope of the post will be extended to offer support to families affected by haemophilia and hepatitis as well as HIV. Interviews for a suitably qualified person will take place shortly.



*The BFG lends a **helping hand** to children and families.*

Amanda Conquy, Director of the Roald Dahl Foundation, commented: "The work of this post goes right to the heart what the Foundation is aiming to do. We believe that by funding this post we will be helping to improve the quality of life for hundreds of families throughout the UK." "Roald Dahl is well-known for supporting haemophilia related causes," added John Berry, the Society's Head of Fund Raising. "However, this is the first time the Foundation has directly supported the Society. We are delighted to be working in partnership with such a forward-thinking and progressive trust for the benefit of families living with haemophilia."

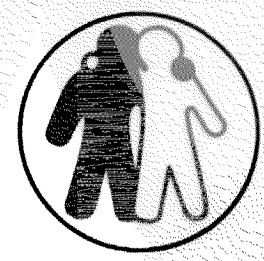
HEPATITIS C CAMPAIGN UPDATE

The hepatitis C campaign has passed through a quiet period over the summer, as Parliament has been in recess. There was a high spot just before the MPs left for their summer break when an adjournment debate was held in the House of Commons on the issue of hepatitis C. Unfortunately the Government position remains unchanged. The campaign will build up more momentum in the autumn, when the Society again resumes pressure on the Government.

The tactic of members writing to MPs has been very successful so far and the Society would like to thank all of those who have done so. If you haven't written to you MP on the issue yet please drop them a line, or visit your local MP at their surgery to talk about the subject and how hepatitis C affects you.

The Society still needs to locate people with haemophilia and hepatitis C who are willing for their stories to be told to the press. If you are interested please contact Graham Barker at the national office.

We are also trying to get as much information as possible on hepatitis C to our members, and elsewhere in this edition of the Bulletin are articles on interferon, drugs to avoid for people with hepatitis C and the work to date of the Society's hepatitis C researcher.



THE HAEMOPHILIA SOCIETY

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Editor of The Bulletin
Andy Cowe

EDITORIAL by Bulletin editor Andy Cowe

The issue of what services should be available in haemophilia treatment centres is of interest to all people with haemophilia. In this edition of the Bulletin we report on the work of the UK Haemophilia Centre Directors' Organisation in the accreditation of Comprehensive Care Centres (CCCs). This process has been very important in ensuring that those Centres designated as CCCs provide a complete range of services for haemophilia treatment.

Unfortunately there are only 21 CCCs in the UK. This means that many people will still have to travel, sometimes large distances, to gain access to the facilities of a CCC.

We welcome the formal accreditation process for Centres and applaud the hard work that has been put in by the UKHCDO. There is still some way to go before a truly comprehensive care service is available in the UK for the treatment of haemophilia, but the work done by the UKHCDO is an important step on the way.

On the front page of the Bulletin we report on a major development in the services provided by the Society. Support for families affected with haemophilia and HIV or hepatitis is vital. The problems caused by these viral infections do not affect the infected individual alone, but can have serious effects on the entire family. The financial help that the Society has received from the Roald Dahl Fountadion will enable the appointment of a Children and Families worker to ensure that the services needed by affected families are available on a nationwide basis.

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.

In this issue

PATIENTS INFLUENCING PURCHASERS

The Haemophilia Society is taking part in a unique three year project that is looking at ways that patient groups can work with health authorities to influence the services that are provided. The project is being run by the Long-Term Medical Conditions Alliance (LMCA) which is made up of over 40 charities that work with and support people living with long term conditions. The Haemophilia Society was a founder member of the LMCA.

The project will aim to develop good practice on how patients can work with health authorities to produce the services that patients want. Six different health authorities will each work with three different patient groups. In addition to developing services that reflect these specific conditions, the health authorities will produce a written statement and set of guidelines about how they will involve people with long-term medical conditions in the future development, monitoring and evaluation of services. The fundamental philosophy behind the project is that the person living with the condition is the expert, and that health authorities must find ways of listening to patients so they can develop services that meet patients real needs.

As part of the project the Haemophilia Society will be working with Walsall Health Authority. Members of the Society living in this area will have the opportunity of participating in this project. For further information on the project or the LMCA contact Graham Barker at the national office.

COMPETITION PAYS DIVIDENDS

A Christmas card sent to North West Group Chairman Norma Guy's office paid dividends for the Society.

The card was from Tunstall Telecom and was sent to the staff at the Inner Control Centre, where Norma works. Included with the card was a competition to explain what the Tunstall Telecom logo, which looks like a coat of arms, actually meant. One of Norma's colleagues, Anne Booth, decided to enter the competition and won the first prize of a donation to the charity of her choice.

"Anne is involved in a lot of charitable work, and there were any number of charities that she could have chosen to give the money to," said Norma. "She very kindly decided to support the Haemophilia Society as well as a unit at Bolton District General Hospital.

Norma (left) is pictured receiving the cheque for £500 on behalf of the Society with, from the left, Dr Poyner of Bolton District General Hospital, a representative of Tunstall Telecom and Anne Booth.

JUMP TO IT MANDY

Daredevil Hepatitis Researcher Mandy Cheetham is doing a parachute jump to raise funds for the Society.

The 2,000 feet jump will take place at Headcorn, near Maidstone in Kent in October. Mandy has taken part in numerous fund raising activities for a variety of good causes over the years. This is the first time she has done a parachute jump, however. "I'm really looking forward to it," said Mandy without a trace of apprehension. "I hope to get a lot of sponsors and really make a success of it". Go for it, Mandy!

You can contribute to the success of Mandy's jump by collecting sponsorship for it. A form has been included with this Bulletin.

ANNUAL DRAW UPDATE

Annual Draw tickets and badge orders are pouring in to National Office. Give us a call if you need extra tickets or Christmas card leaflets.

BEST WISHES TO BRENDA

Sister Brenda Brown retired from the Lincoln Haemophilia Centre after many years of service on 24 May 1995.

The Lincoln local group and all of her patients at Lincoln County Hospital would like to express their gratitude for her efforts on their behalf over the years.

Her esteem among people with haemophilia was marked during the Lincoln group's summer outing to Fun Coast World in Skegness when the group presented her with a Royal Doulton Crystal vase and card. Brenda will continue to be a member of the Lincoln group, so Society members will be able to keep in touch with her.

The Society wishes Brenda and her husband, John, a happy retirement.

LIVING WITH VON WILLEBRAND DISEASE

A tale of three generations

The Baker family have lived with von Willebrand disease for three generations. Unlike haemophilia von Willebrand disease can affect men or women. The Bulletin spoke to Maureen Baker about how the family had coped.

The story really starts with Robin Baker, husband to Maureen. Maureen knew that Robin had a bleeding disorder called thrombocytopoenic purpura, diagnosed at the Radcliffe Hospital Oxford when he was two, with bleeds treated with snake venom, gauze and adrenaline chloride. She talked about it at length with him before they got married. They also talked about it with their doctor. "This was 35 years ago," said Maureen "we didn't know much about it and the doctor hadn't seen many cases. The doctor - who was very helpful - reassured us that the condition couldn't be passed on to the next generation. Unfortunately he was wrong in this opinion."

Robin and Maureen had their first son, Stephen with no mishap. But when their second son, Chris, arrived there were problems. At the age of four Chris needed a minor operation, and the hospital informed the family that Chris had a bleeding disorder, so the operation was postponed. "We hadn't known that there was anything wrong at all," said Maureen. "Chris did bruise easily and have the occasional nosebleed, but nothing out of the ordinary."

The next arrival in the family was Diana, who had no problems, and finally Angela arrived. Angela had fingerprint bruising when she was born, which was a sign of problems to come. At nine months Angela fell and cut the inside of her mouth and lip. "She bled and bled," said Maureen. "We took her to the hospital and they stitched the cut, but it continued to ooze. They kept her in for a while to do some blood tests.

Problems

"Next we were visited by our doctor who said that Angela had von Willebrand disease. I had already guessed this from the problems that she had with the cut, so it came as no surprise."

The family then had tests at Great Ormond St Hospital, which confirmed the diagnosis - Robin had von Willebrand disease, as did Chris and Angela.

The treatment for von Willebrand disease has improved a lot over the years. "When I met Robin he was treated by blood transfusions, or in the case of a bad nosebleed with packing and snake venom. Now he's treated with factor VIII in the case of bad bleeds, but can also use Cyklokapron for more minor ones."

Chris, who now holds down a good job as an electrical maintenance engineer, has very few problems, though what problems he did have were caused by trying to keep up with his brother, but Angela was in and out of hospital with bleeding problems as she grew up. "Angela has a few difficulties with her ankles as a result of her bleeds, but these don't seriously affect her walking," said Maureen. "She once had quinsy, which led her to have throat surgery because the ear nose and throat doctor would not listen to her when she told him she was to see a haematologist before anything was done. The junior doctor had not read her notes, and unfortunately this still occurs. Angela had her appendix out when she was 16."

Chris and Angela had no real difficulties at school. "We made sure that we talked to the head teacher right from the start," said Maureen. "We also had a talk with each of the form teachers as they moved up the school. It helps if the teacher is fully informed about a child's bleeding disorder and knows what to do in the case of an emergency."

The third generation of the family with von Willebrand disease are Angela's children Hannah and Sean. They are both treated with injections of factor VIII. "They've had no major problems," said Maureen. "But it is important to see things from their point of view. For instance Sean had a fall at school a few months ago and had a very bad nosebleed. The school 'phoned Angela and he was taken to hospital and his nose was packed with gauze. For a young child this can be very frightening, and it is important for the parent to be there to reassure them and let them know that everything will be all right."

Nervous

Sean was a bit nervous about going back to school after this episode, but once there he soon settled back in, and the teachers were very supportive.

Maureen has vast experience of living with von Willebrand disease from her husband, children and grandchildren.

Left to right - Robin, Hannah, Angela and Sean, Chris.

The Bulletin asked her what advice she would give to parents of children with von Willebrand disease. "My advice is don't panic when they have a bleed," she said. "I know it sounds very obvious, but with a child it's very important. Children can get into a state very easily, which can in turn upset the parent. If the child sees the parent is upset they become even more frightened. It's a vicious circle. From an early age tell your child in as simple terms as possible what is wrong, don't wrap them in cotton wool. Children with von Willebrand disease have the same chance as any other child in life. I know that sometimes Stephen and Diana were jealous of the attention Chris and Angela had, but all parents manage to spread their love just that little bit further. Diana once said "The only way I got to go to hospital was to go and work there" (she is a nurse).

"When my children had bleeds I always did my best to remain very calm. I'd try to reassure the child that it may hurt now, but it won't hurt for very long and we are doing our best to help. You have to stay calm for the child's sake. After the bleed was all over I'd sometimes go to pieces, but not until it was safe to do so."

BRENDAN FOSTER JUNIOR SPORTS AWARD

The presentation of the Haemophilia Society Awards at the AGM earlier in the year was missed by one very important winner.

Unfortunately Daniel Jolley, the winner of the Brendan Foster Junior Sports Award was unable to attend. As a result he received it a little later than planned from Society Director of Services, Graham Barker during a recent visit to Kent.

Daniel is nine years old and received his award for his achievements in tennis, which are very impressive. He began playing in 1992, and by the beginning of 1994 had gained all of the Lawn Tennis Association short tennis awards at gold level. In 1993 he played in the Trevor May Kent open short tennis and won his group. In the same year he was runner up in the Farringdon school short tennis tournament in Chislehurst. The following year he again won the Trevor May open and began to compete at tennis as well as short tennis. In 1994 he won a starter tennis competition, the under 9s club competition, was the under 9s winner in the Midland Bank schools' tennis tournament and, with his doubles partner, won the Orpington short tennis doubles competition.

This summer he has represented his club in the Ashford under 13s league and has won all of his doubles matches with the help of his partner Jenny Poole. He has also played quite a few singles matches and successfully beaten 12 and 13 year olds on a number of occasions.

Presenting the award, Graham Barker commented that Daniel's achievements in tennis were an example to young people with haemophilia. His

efforts, and successes, showed that haemophilia need not necessarily be a bar to children playing a full part in sporting activities.

Daniel will use the £50 award to buy a new tennis racquet.

BLOOD PRODUCTS AND SAFETY

The tragedy of HIV and more recently hepatitis C, has taught the haemophilia community that safety is only the result of constant vigilance. To this end, in spite of the major steps that have been made in recent years, the Society is keeping the whole area of product safety under close scrutiny.

Below we reprint an extract of a recent letter published in the 19th August edition of the BMJ by Prof Ted Tuddenham, a member of our Medical Advisory Panel and Dr Mike Laffan from the Hammersmith Hospital.

..."Purification alone will not eliminate the risk of infection but it substantially reduces the load of known and unknown viruses. Hence the issue of purity becomes one of safety and therefore the purer the factor VIII the better.

"Recombinant factor VIII is therefore the treatment of choice, given its freedom from viruses derived from plasma (adding albumin, which has an excellent safety record, does not alter this). But recombinant factor VIII costs 45p per unit compared with 25p for high purity and 18p for intermediate purity factor VIII. The NHS struggles to pay for recombinant factor VIII. In the meantime, the spectre of unknown virus remains, and those who can pay for purity and safety are right to do so."

The Society agrees with this position. There are concerns about the use of recombinant, in particular a risk of inhibitors developing in previously untreated patients, however moving treatment from intermediate products to high purity and then recombinant must be an important goal for us.

Creutzfeld-Jacob Disease and Parvovirus Concerns about the reliance on plasma derived products have been the subject of recent medical press coverage of the possibility of the spread of Creutzfeld-Jacob Disease (CJD) and parvovirus through blood products.

Parvovirus is a common virus, particularly amongst children, which may cause an illness which normally passes without any long term effects. There is now considerable evidence that parvo can withstand most of the currently used viral inactivation steps. Parvo itself may not be a cause of great concern in the normal course of events, however it does show that some viruses can get through the net, and it is the as yet unknown viruses that worry us most.

CJD is more controversial. It is a very rare disease which attacks the brain, and is caused by a particle smaller than a virus known as a "prion".

There is no evidence that this is, or has been, transmitted by blood products.

However, the same principle applies as for parvovirus. We do not know what is out there that may cause a problem at some time in the future. Until then, restrictions on hospital budgets are restricting our access to probably safer products.

THE RED RIBBON PAGE

Travel and HIV

Travel for people with HIV remains a problem, particularly to more "out of the way" countries. Russia has recently passed a law requiring HIV tests for those foreigners staying for more than three months. Many people, particularly those wishing to travel to the USA, just take the risk with no problems, that is a matter of individual choice. If you have any problems, please call the Society.

Study into HIV and AIDS

There has been widespread reporting by the media of a study carried out on behalf of the United Kingdom Haemophilia Centre Directors' Organisation into HIV and mortality.

The study, which was reported in a letter to Nature magazine on 7th September, examined the total membership of the British National Haemophilia Register between 1977 and 1991 - a total of 6,287 people - and looked at the fates of those who were infected with HIV and those who were not.

It will come as no surprise to members of the Society that the results have been hailed as establishing a definite link between HIV and AIDS.

The study showed that the death rate from all causes among those people with haemophilia infected with HIV has been roughly ten times greater than among the uninfected population and that the death rate among the infected is not influenced by the clinical severity of their haemophilia.

The Haemophilia Society has welcomed the research as it means that the scientific community can now concentrate their attention on finding an effective treatment for AIDS rather than arguing over its cause.

It also throws into clear focus the dangers of relying on plasma derived products for treatment of haemophilia and is a good argument for the use of genetically engineered products to avoid future infection by as yet unknown viruses that could be present in the blood supply.

Birchgrove Complementary Therapies Programme - Birmingham 14th/15th October

The Birchgrove Complementary Therapy Weekend is an excellent opportunity for people with haemophilia and HIV to discover some of the many holistic therapies that are available. Many people have become increasingly interested in the benefits offered by the appropriate use of complementary therapy techniques. The benefits of complementary therapies may be gained by everyone whatever the complexity of their symptoms or the severity of their ill-health.

For more information, contact the Birchgrove Group.

Internet:

misc.health.aids
The Usenet newsgroup, misc.health.aids, is the only world-wide forum dedicated to a free and open exchange of ideas about AIDS. There are over 42,000 readers of misc.health.aids world-wide. Site address: http://anansi.panix.com:80/userdirs/jscutero/

Marty Howard's HIV/AIDS Home Page

A comprehensive listing of net sites providing information on: HIV/AIDS-related education, mailing lists, support groups and social security information, with a special section highlighting services and resources new to the net.Site address: http://www.smartlink.net/~martinjh/

Contacts

The Macfarlane Trust:
Tel: 0171 233 0342
PO Box 627, London
SW1H 0QG

The Birchgrove Group:
Tel: 0345 697231 Lo Call
PO Box 313, Canterbury,
Kent CT1 1GL

NAM Publications:
52 The Eurolink Centre,
49 Effra Road,
London SW2 1BZ
Tel: 0171 737 1846

Service Shorts

The Society's Services Committee is the group that is responsible for overseeing on a day to day basis, the work of the Society in terms of the services that the Society makes available to our members. These range from the adventure holidays, to help with benefits and grants, to publications and lobbying the Department of Health and Haemophilia Centres for the best possible treatment and care. Future Bulletins will include a round up of some of the issues that we have been looking at over the last few months. In many cases you will read more about them elsewhere in the Bulletin, but we hope you will find this page useful.

BBC CARDIAC ARREST

Many people will have seen a very distressing incident during this programme depicting a person with haemophilia dying from a nosebleed. The Society, and many members, complained to the BBC, who have agreed that the following announcement will be made during the next series of Cardiac Arrest.

"An episode in the last series featured a patient with haemophilia whose nosebleed developed into a torrential haemorrhage from which he quickly died. We would like to make clear that a haemorrhage of this kind is not typical of haemophilia, and is in any case a very rare event."

The Society is continuing discussions with the BBC about the possibility of strengthening this statement and is also registering a complaint with the Broadcasting Complaints Commission about the programme.

TWINNING THE SOCIETY

The level of haemophilia care in most of the rest of the world is very poor, or non-existent. There is however a great deal that we can do to help people with haemophilia who are less well served than we are. The World Federation of Hemophilia has encouraged national societies to twin with a society from another country. We in the UK have decided to establish a twinning operation with the Russian Haemophilia Society.

This is going to be a major enterprise, as the situation in Russia is very poor. We hope to arrange for Russian doctors to come to the UK for training, some Haemophilia Centres have already offered to help. We would also like to encourage members to establish contacts, through exchanges, holidays and pen-pals. This is a very exciting move for the Society, and we will be meeting with a group of Russians to plan further activities in October.

THE HAEMOPHILIA CENTRE DIRECTORY

A new edition of the Haemophilia Centre Directory is under preparation and should be published by the end of the year. Whilst this is not a "Good Centres Guide" with ratings of one syringe up to five, it will help when travelling, and indeed to see if there is another Centre that might be more suited to your needs.

On a wider point, if you ever have concerns about your Centre, please let us know. We are always glad to help members raise issues of concern with their Centre Director, and to try and ensure that people are happy with the service that they are getting.

HEPATITIS ROADSHOWS

The Society arranged four Hepatitis Roadshows in September. The meetings were held at Glasgow on 4th September, Cardiff on 19th September, Liverpool on 28th September and Belfast on 29 September.

The London Hepatitis Roadshow will be taking place on Saturday 11 November at the Scandic Crown Hotel, Victoria, not the 18th November as previously advertised. Speakers will include liver specialist Dr Mutimer and Edinburgh Centre Director Dr Chris Ludlam. For further details please contact Evangelie at the national office. The Roadshows have all been supported with an educational grant from Bayer.

HEPATITIS CAMPAIGN

The campaign has been quiet during the summer, but once Parliament returns in October, you can be assured that we will be piling on the pressure again. We will also be having a presence at all the party conferences in order to keep our contacts up.

HEPATITIS BOOKLET NOW AVAILABLE

The Society has just printed its new booklet on hepatitis. Focusing on hepatitis C, the booklet is intended to provide basic information on the disease for people with haemophilia. It also contains a checklist on what to expect from your centre.

The booklet, which has been produced with an educational grant from Schering Plough, is being sent to all members of the Society and a copy is enclosed with this edition of the Bulletin.

THE HAEMOPHILIA HIGHWAY

For those surfing the Internet, the Society is now on-line at 100711,1677@ GRO-C (Try conventional means of communication as well, as there are bound to be a few teething problems.)

There is also now a (US based) haemophilia homepage, to which we hope to contribute soon. (Note American spelling) http://www.web-depot.com/hemophilia

COMPREHENSIVE CARE FOR HAEMOPHILIA IN THE UNITED KINGDOM

by Dr Brian Colvin, Chairman of the United Kingdom Haemophilia Centre Directors' Organisation

Over forty years ago pressure from people with haemophilia and the enthusiasm of the Oxford Group began the process which led to the establishment of a network of haemophilia centres throughout the United Kingdom. The work was initially encouraged by the Ministry of Health and the Medical Research Council and it was soon possible to designate a series of Reference Centres which had a particular expertise in laboratory diagnosis and treatment.

In 1968 the Ministry of Health published a memorandum, HM(68)8, concerning "Arrangements for the care of persons suffering from Haemophilia and related diseases" which contained a list of 36 Haemophilia Diagnostic and Registration Centres and criteria for the proper management of haemophilia.

At about this time the first meeting of the United Kingdom Haemophilia Centre Directors' Organisation (UKHCDO) took place in Oxford. During attempts to coordinate the organisation of haemophilia care in London a three-tier system was proposed and by 1976 new national arrangements were set out in HC(76)4 defining Reference Centres, Haemophilia Centres and Associate Haemophilia Centres.

By 1989 it was felt that a regional system would be more appropriate because of the pace of development of services across the country and because it was hoped that each region would be better able to co-ordinate haemophilia care for its own population. The Reference Centre Directors had already formed an Executive Committee and this was replaced by the Regional Centre Directors Committee which held its first meeting on 11 September 1989.

In retrospect the 1970s may have represented the high point of the centrally managed NHS and during the 1980s signs appeared of the organisational and financial strains which led to Mrs Thatcher's NHS Review in 1989. This heralded the end of a co-ordinated and managed approach to health care and the old Regions and Districts are now being replaced by the "market" of trusts, purchasers, providers, mission statements, business plans, cost pressures, cost improvement programmes and bed closures.

Fortunately for people with haemophilia it was possible for the Haemophilia Society and UKHCDO to discuss with the Department of Health the best way to provide haemophilia care and on 25 June 1993 a new Health Service Guidelines document, HSG(93)30, was published by the NHS Management Executive. This recognised the special position of haemophilia as a condition where regulation of the contracting process was desirable and the concept of comprehensive care was defined in a way which purchasers would be able to understand.

Two types of haemophilia centre, Comprehensive Care Centres (CCCs) and Haemophilia Centres, were recognised and criteria were laid down for their designation. It was acknowledged that all patients with haemophilia in the United Kingdom should be able to obtain the full range of comprehensive care facilities, whenever necessary, although this did not imply that each and every patient should be registered with a CCC.

In 1994 UKHCDO responded to the rapidly changing health care market by preparing a Constitution which secured a clearer framework for its functions and enabled it to be registered as a charity. At the same time a questionnaire was prepared and distributed to all haemophilia centres asking them whether they would wish to be included in the list of CCCs or would prefer Haemophilia Centre status. Applications were studied by a small panel of independent experts and those centres selected for CCC status which had not yet been through the audit process were visited by a panel of two assessors appointed by the Regional Centre Directors Committee. The current list of CCCs and Haemophilia Centres is given in the table but should not be regarded as final or complete since haemophilia care and the organisation of hospitals and trusts continues to evolve rapidly. It is very important to understand that excellent and comprehensive care may be offered at many centres which do not appear on the CCC list. This particularly applies to those centres located in towns or cities where rapid organisational change is taking place and to smaller centres which do not treat the necessary number of severely affected patients (which is an essential element in CCC recognition).

It should also be noted that in some cities the adult and children's centres have combined so that comprehensive care at all ages in one location can be guaranteed. It is particularly hoped that additions can be made to the CCC list in the West of England where the comparatively low population density makes it difficult for any one centre to satisfy the criteria for a CCC.

It is also necessary for the UKHCDO to decide how to regulate the CCC list for the future and whether or not to move from a regionally based committee structure to one based on CCCs. For the past two years we have concentrated on the best way to recognise CCCs but we also need to decide how to deal with the changes which may result in a CCC being unable to meet the standards set in HSG(93)30. Such changes could easily occur as a result of population shifts or the movement of staff without any suggestion that the quality of the remaining services was falling, so the loss of CCC status should not be seen as a criticism of the care a centre is able to provide. Nevertheless careful attention will have to be paid to this aspect of the regulation of haemophilia centre status and the problems which could arise in the future should not be underestimated.

As we move towards a more mature new NHS, a general election and the next century we must continue to focus on our objective of providing the best possible care for the whole haemophilia population in the United Kingdom. It may seem that we are in danger of making life unnecessarily complicated for our carers and our patients but UKHCDO is firmly committed to the maintenance and development of the service which was created by Professor Macfarlane and his colleagues so many years ago.

HAEMOPHILIA CENTRES

Aberdeen	Eastbourne	Peterborough
Ashford	Epsom	Plymouth
Bangor	Exeter	Portsmouth
Bath	Hammersmith	Roehampton
Bedford	Harlow	Salisbury
Blackburn	Harrogate	Shrewsbury
Bournemouth	Hastings	Southampton
Bradford	Hereford	St George's Tooting
Brighton	Hillingdon	St Mary's Paddington
Bristol	Huddersfield	Staffs (North) Stoke
Bristol Children's	Hull	Sunderland
Bury St Edmunds	Inverness	Swansea
Camberley	Ipswich	Taunton/Yeovil
Canterbury	Kettering	Torquay
Carlisle	King's College Hospital	Truro
Carshalton	Kingston	Tunbridge Wells
Chatham	Lancaster	UCH
Chelmsford	Lewisham	Southend
Chelsea and Westminster	Lincoln	Wexham Park (Slough)
Chertsey	Luton and Dunstable	Whitehaven
Chichester	Mayday Thornton heath	Winchester
Colchester	Middlesborough	Wolverhampton
Coventry	Milton Keynes	Worcester
Derby	Norfolk and Norwich	Worthing
Devon North Barnstaple	Northampton	York
Dorchester	Northwick Park	
Dundee	Newport Gwent	

COMPREHENSIVE CARE CENTRES

Alton	Liverpool (Adults and Children's)
Belfast	London (Royal)
Birmingham	Manchester (Royal)
Birmingham (Children's)	Manchester (Children's)
Cambridge	Newcastle
Cardiff	Nottingham
Edinburgh	Oxford
Glasgow (Royal and Children's)	Royal Free
Great Ormond Street	St Thomas' and Guy's
Leeds	Sheffield (Adults and Children)
Leicester	

THE SOCIETY'S VIEW ON COMPREHENSIVE CARE

The formal accreditation of the 21 Comprehensive Care Centres marks the culmination of a great deal of work by the Society and the UKHCDO.

The audit process leading to accreditation of CCCs was prompted in no small part by the publication of the health service guidelines HSG(93)30 in 1993 on the provision of haemophilia treatment and care. These guidelines were largely due to an initial approach from the Society to the government, backed by considerable research. After persuading the government that new guidelines were necessary, there followed a lot of work by the Society and the UKHCDO in their assembly.

The accreditation of CCCs has taken several years but it is a major step forward in the journey towards the target of uniformly excellent haemophilia treatment for all people in the UK. But there is still a long way to go. There are only 21 CCCs nationwide able to provide all of the services that people with haemophilia may need and there are areas of the country that do not have a CCC.

Haemophilia Centres, while providing a good standard of care do not usually have the facilities to deliver the complete range of specialist treatment. Many are small, treating only a few people, and so do not have the resources to deal with major problems that people with haemophilia may face. In time the Haemophilia Society would like to see the audit and accreditation extended to all Haemophilia Centres.

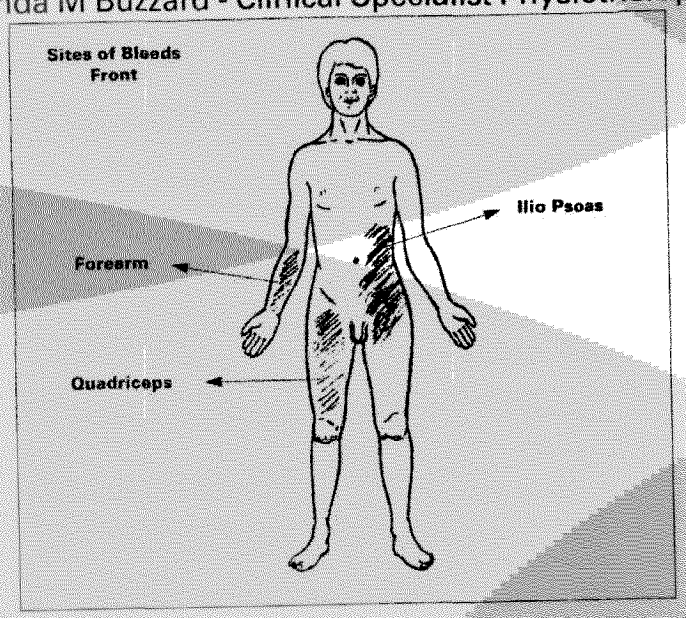
PHYSIOTHERAPY AND MUSCLE BLEEDS

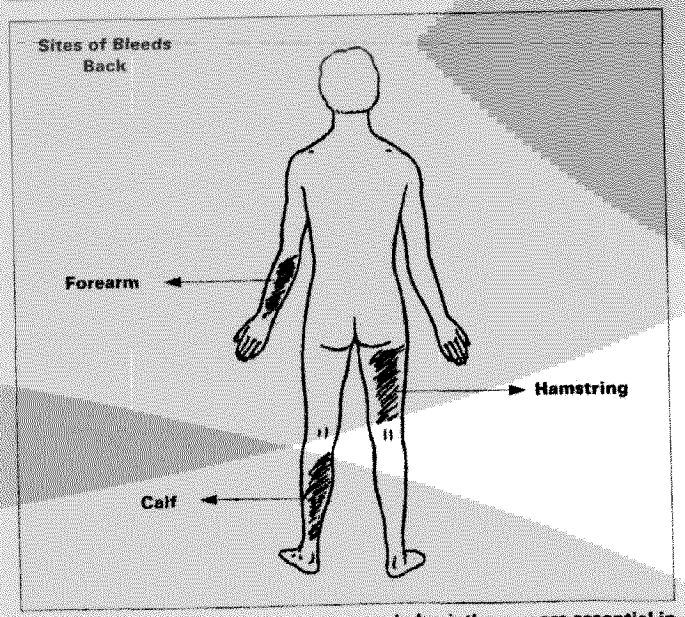
Brenda M Buzzard - Clinical Specialist Physiotherapist Royal Victoria, Infirmary, Newcastle upon Tyne

The fundamental difficulty facing those with haemophilia is bleeding into the joints and muscles. Emphasis has been placed upon the early recognition and treatment of joint bleeds in order to prevent disability in later life. However, for those with severe factor VIII or IX deficiency muscle haemorrhages may be more common and, like joint bleeds, may occur spontaneously or with minimal injury. For those with moderate or mild haemophilia muscle haemorrhages are often a result of a sporting injury or a direct blow. Common silts for muscle haemorrhages are the iliopsoas (or retroperitoneal), quadriceps (or front of thigh), hamstrings (back of thigh), calf and forearm.

Bleeding into these muscles may affect a single muscle or a group such as the quadriceps. They may also be deep or superficial and it is important to differentiate between the two. Consult your haemophilia centre for assessment if in doubt. Superficial or subcutaneous haemorrhages rarely produce deformity; however deep muscle haemorrhages can lead to complications such as nerve compression and joint contractures if left untreated or inadequately treated. For example an inadequately treated bleed into the calf can result in the formation of scar tissue, producing an equinus deformity of the foot and ankle causing the person to walk on his toes.

Complications of Muscle Bleeds:
Compartment Syndrome
The muscles of the lower limb and forearm run longitudinally and are divided into separate compartments by tough, thin layers of connective tissue. The layers surrounding the individual compartments are tight and inelastic and therefore any swelling inside a compartment will cause a rise in pressure which in turn compresses the muscles, nerves and blood vessels. This causes symptoms such as pain, tenderness, muscle weakness and eventually numbness and loss of movement in the affected limb. This condition is called 'compartment syndrome' and warrants prompt attention.





Treatment of Muscle Bleeds
As with joint bleeds early diagnosis, factor replacement therapy and physiotherapy are essential in order to prevent complications. The following table lists the common sites of muscle bleeds, their signs and symptoms and suggested treatment.

Site of Bleed	Signs and Symptoms	Suggested Treatment
Ilio-Psoas or Psoas	1) Pain lower abdomen or groin 2) Hip and knee bent 3) Numbness front of thigh 4) Weak quadriceps	1) Replacement therapy for several days 2) Hospital admission 3) Strict bed rest 4) Gradual physiotherapy input to restore function. Recovery can take up to 18 months
Quadriceps or Hamstring Bleeds	1) Pain 2) Swelling (hard and tense) 3) Warmth 4) Difficulty straighten or bend knee 5) Difficulty weight bearing 6) Bruising (if direct trauma)	+ or - Bed rest depending on sevrity 1) Replacement therapy 2) Pain relief ice, pulsed short wave diathermy 3) Elevation of affected area 4) Early physiotherapy for pain relief, PSWD, massage, muscle stretching and strenthening
Calf	1) Pain 2) Swelling (tense) 3) Warmth 4) Decrease in ankle movements 5) Difficulty to weight bear 6) Bruising	1) Replacement therapy 2) Elevation of limb 3) Rest, use of crutches 4) Early physiotherapy 5) Home exercises
Forearm	1) Pain 2) Swelling 3) Decrease movement fingers, wrist and elbow 4) May have numbness of fingers, forearm	1) Replacement therapy 2) Elevation 3) Splint 4) Exercise/ physiotherapy

If the muscle bleed is the result of a sporting injury then care must be taken to ensure that full range of movement has been restored *and there is no pain prior to* returning to sporting activity. The physiotherapist will direct accordingly and give advice regarding stretching exercises, warming up and down. Deep frictional massage is very effective in the treatment of muscle haematomas by preventing the formation of scar tissue. The treatment of sports injuries should be individual and the aim of early treatment is to relieve pain, minimise bleeding and soft tissue damage and limit inflammation. Exercise increases the mechanical and structural properties of joints and muscles and therefore should be started as soon as the healing of the injury permits.

For those with haemophilia the following regime of self treatment combined with factor replacement therapy should be adopted.

R - Rest
I - Ice
C - Compression
E - Elevation

Rest
Complete rest from all activities is often unnecessary, but some rest, particularly of the injured area, is essential. Most soft tissue bleeds require a total of 48 hours rest in order to reduce the swelling. A deep haematoma of the thigh may progress to a hardened scar if exercised too early. Following an iliopsoas bleed strict bed rest is necessary, usually in hospital. Crutches may often be used to relieve the pressure on a lower limb bleed. Splinting is another form of rest.

Ice
Ice is the most successful of the cold treatments. Ideally, crushed ice should be used in a dampened tea towel and placed over the affected area. Care must be taken to prevent 'ice burns' by always placing a damp towel between the skin and the ice or other cold source. Ice should be applied for about 10-15 mins, two hourly in the first 48 hours. The effect of cold is to restrict the blood supply to the injured area, which will minimise the swelling. The 'trusty' pack of frozen peas in the ice box can be used as a substitute.

Compression
Swelling occurs following any injury and the greater the swelling the more painful the injury. The sooner the swelling is dispersed the better. There are various forms of elasticated bandages and tubular dressings available to apply compression, but care needs to be taken when using them. They should not be too tight. Compression in conjunction with ice therapy is most effective

Elevation
By elevation or raising the injured limb gravity helps to relieve the congestion in a bruised area by increasing the blood flow away from that area. The injured limb should be raised above the level of the heart.

RICE is the most common and effective form of home treatment and when followed properly it enhances the next stage of rehabilitation. For this your physiotherapist will advise you on a programme of increasing activities including muscle stretching sessions, massage and strengthening exercises until full recovery and restoration of normal function is achieved.

WHAT IS INTERFERON?

by Dr John Hanley, Lecturer in Haematology
Dr Christopher Ludlam, Consultant Haematologist Royal Infirmary of Edinburgh

Interferon is a topical subject because many individuals with haemophilia and hepatitis C virus infection are being offered treatment with this drug. This article discusses what interferon is and when it may be used as well as some of its potential side-effects.

History: Interferon was discovered in 1957 by scientists who were studying viruses.
They identified a substance that "interfered" with virus replication and called it interferon. It is now known that interferons are a family of proteins which are produced by the body in response to virus infections and perform a variety of other roles linked with the immune system. Over the last 40 years much medical research has been devoted to the study of interferons and it has been found that interferon preparations are extremely useful in treating patients with a wide range of conditions including diseases caused by viruses. In people with haemophilia interferon has been used to treat both hepatitis B and hepatitis C.

The first commercially available interferon was made from human white blood cells. This process was technically difficult and resulted in the production of a relatively small amount of interferon. With the application of gene technology it became possible to produce larger amounts of synthetic interferon ("recombinant interferon").

Administration: Interferon is available in packs containing syringes "ready for injection" to make treatment easy. Interferon is usually given by an injection just beneath the skin (subcutaneous). Most patients find it easy to self-administer the injections and apart from occasional irritation around the site of injection there are seldom other problems. The dose (measured in "megaunits") and duration of treatment with interferon vary according to the condition being treated. In addition changes in dose may be required during treatment depending on response and side-effects.

Side-effects: In the early stages of treatment many individuals experience 'flu-like" symptoms such as nausea, sweats, tiredness and muscle aching. The severity of these symptoms varies between patients and are often helped by taking the injections at bed time along with two tablets of paracetamol. Some people report minimal problems whereas others are considerably upset. These symptoms usually subside after 1-2 weeks as the body gets used to the interferon; most people are able to carry on normal activities during treatment. A minority of individuals do, however, experience ongoing problems with lethargy and may be unable to tolerate a full course of interferon. In addition interferon may occasionally reduce the activity of the bone marrow so regular blood checks should be performed during treatment. Occasionally other side effects may occur such as hair loss or mood changes.

Hepatitis B Virus (HBV): Interferon has been used successfully to treat active HBV infection but this occurs in only a minority of people who became infected prior to hepatitis B vaccine becoming available. The introduction of screening of blood donors, virus-inactivation procedures in the production of factor concentrates in addition to the availability of the vaccine has led to HBV being much less of a problem than previously.

Hepatitis C Virus (HCV): Almost all individuals who received factor concentrates prior to the effective use of virus inactivation steps, were exposed to hepatitis C. In contrast to HBV, chronic infection with HCV is common. The virus causes liver inflammation and may, over a period of many years, cause serious liver scarring and lead to cirrhosis. Interferon is the only drug licensed for the treatment of HCV and a typical dose is 3 megaunits three times per week for six months. Of those treated about 25% of patients clear the virus. Younger individuals and those infected with certain sub-types of HCV are more likely to respond to interferon. Those who do respond usually clear detectable HCV from the blood within 8-12 weeks of starting treatment. So it is possible to identify those who are responding at a relatively early stage of treatment. Individuals who do not show a response to treatment within 8-12 weeks should probably stop interferon as there is little benefit from continuing for longer. In individuals who do respond, relapse may occur once interferon is stopped. Recently published studies suggest that better results may be obtained using higher initial doses of interferon at the beginning of treatment and that continuing treatment for 18 months may reduce the relapse rate.

Interferon is not a universal panacea for HCV but it appears to offer benefit to some. Each individual's circumstances should therefore be fully discussed at the Haemophilia Centre to ensure that the pros and cons of therapy are known prior to starting treatment.

HCV RESEARCH UNDERWAY

The picture up to now by Mandy Cheetham, Society Hepatitis Researcher

Many thanks to everyone who has taken part so far in the Society's hepatitis research.

The feedback which you have given me is an essential part of ensuring that the Society meets your needs. Your ideas and comments have already been put to good use in the planning of new services. They will also help to inform the campaign for help from the government by giving a clear picture of the impact HCV is having on the quality of life for Society members.

So far, I have written to 111 Centres providing services for people with haemophilia and all local groups. I have also designed a questionnaire which I am sending out to those who would be willing to complete it. By the end of September I will have sent out over 350 questionnaires and am hoping for a high return rate.

I am interviewing people face to face and over the phone, so if you or your local group would like to feed back suggestions, I can come out to you.

It is clear, even at this fairly early stage, that people have a variety of specific needs. The most common one people mention is up-to-date information. People have said that they need to feel better informed so that they will know what kinds of questions to ask their Centres about hepatitis C and have the confidence to do this.

It is also worth saying that there is currently an enormous amount of information being published about hepatitis C, some of it contradictory. Haemophilia Centres, the Society and the media vary in their interpretation of this and so people receive different messages.

The Society is considering producing factsheets about different areas of HCV. What areas do you think should be covered? Let us know! It is clear that HCV is having far reaching consequences for some.

People have also said that they would like counselling and support. How do you think this is best provided?

What are your thoughts about a telephone advice line?

Would you attend a local support group for people affected by hepatitis C?

Are you or people you know of having problems getting access to Interferon for funding reasons?

What has been your experience of treatment?

Has your work or schooling been affected by HCV?

Have you got extra financial costs because of HCV?

Some people have made very specific suggestions about services they would like to see provided. I need to know how representative those ideas are. The only way the Society knows whether it is on the right track is if you, its members, give us feedback!

Mandy Cheetham

I've spoken to a wide range of people, but not enough! Don't hold back. This is your chance to let the Society know what you want and what you feel is important. I will be making recommendations in the coming weeks on the basis of what you tell me.

Seize this opportunity. If you have concerns, suggestions or ideas to put forward, get in touch. I'm keen to hear from everyone, particularly women and young people under 25 who have HCV. Your views are currently under represented in the research.

I look forward to hearing your comments - you can contact me at the national office, either in writing or by telephone.

Dear Doctor ...

The answer to this edition's Dear Doctor question comes from Dr Eleanor Goldman, Associate Specialist at the Royal Free Hospital in London.

I have heard that some hay fever tablets, including Triludan should not be taken by people with hepatitis. Is this true, are there others that should be avoided, and if so are there any alternatives that can be used instead?

In the March 1995 Bulletin Dr Charles Hay dealt with problems of drugs or anaesthetics commonly used by people with haemophilia which should not be used when they have hepatitis C. He explained that drugs that are metabol-ised in the liver can be eliminated more slowly than usual, leading to an exaggeration of the therapeutic affect and possibly to increased toxicity.

With most of the old antihistamines drowsiness is a disadvantage, ability to drive or operate machinery may be impaired and the effects of alcohol may be increased. The newer antihistamines such as Triludan (Terfenadine) and Zirtek (Cetirizine) cause less sedation but although drowsiness is rare patients should be aware that it can occur.

Triludan is metabolised in the liver and increased blood concentrations can cause heart arrhythmias, particularly when given with certain other drugs, for example, erythromycin. The manufacturers recommend that Triludan should be avoided where there is significant liver damage but it would seem prudent for people with hepatitis C to seek an alternative antihistamine even when they have mild liver disease.

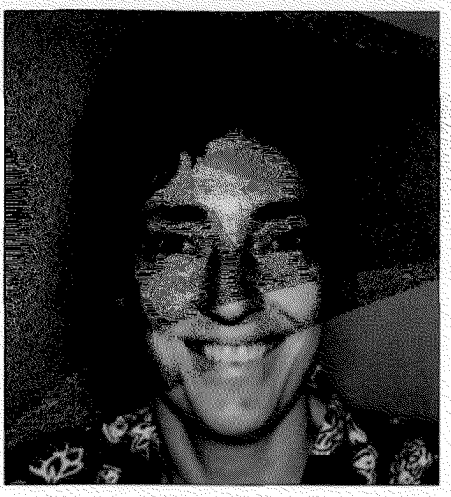
Zirtek is also one of the newer antihistamines which is effective in relieving the symptoms of hay fever and urticaria. It is not metabolised in the liver and would therefore be suitable for patients with hepatitis C. It must be remembered that it is metabolised in the kidney and would be unsuitable for those with any significant kidney disease.

Zirtek is available over the counter if sold under the pharmacist's supervision, for adults and children over the age of twelve years, provided packs do not contain more than 10 day's supply. The dose is 10mg per day (usually taken at night) or 5mg twice a day. The 10mg tablets are scored to allow for division into two doses. Zirtek is not recommended for children under 6 years.

Beconase aqueous nasal spray can be sold over the counter for hay fever in limited pack size. Your pharmacist would be willing to discuss dosage with you.

PROFILE OF MEDICAL ADVISORY PANEL MEMBER DR PAULA BOLTON-MAGGS

Dr Paula Bolton-Maggs is a consultant haematologist and Haemophilia Centre Director at the Royal Liverpool Children's Hospital, Alder Hey - positions she has held since December 1992. She is an expert in factor XI deficiency, having carried out extensive research and published numerous papers on the subject. She recently joined the Society's Medical Advisory Panel.



Dr Paula Bolton-Maggs is a leading light when it comes to factor XI deficiency - she has been researching the disorder for nearly 10 years. She first embarked upon investigating the condition - formerly known as haemophilia C - while at London's Royal Free and University College Hospitals in 1986. Here (with others) she studied the inheritance and bleeding tendency in more than 150 members of 24 families registered at the hospitals' Haemophilia Centres.

Her most recent projects have included looking at the genetic changes and bleeding problems in 30 factor XI deficient families from the North West and, another collaborative venture, the screening of relatives for both known and unknown mutations.

"I'm pleased with my work in factor XI deficiency because I can see the benefits," Dr Bolton-Maggs said. "We now understand the disorder much better than before.

"Also, because the condition is less severe than other types of haemophilia and because it affects fewer people, I've found that patients have been glad that someone has taken an interest in them - that's very rewarding too."

When Dr Bolton-Maggs was at university (Cambridge) she was unsure as to whether to pursue a career in clinical medicine or pure research. "Luckily," she went on, "I was given some excellent advice - that if I did a degree in medicine I would never regret it as, among other things, it makes research easier to do."

In spite of her affinity with the laboratory, Dr Bolton-Maggs maintains that the most enjoyable part of her job is meeting the patients and their families.

"The intellectual part of me enjoys the quest involved in research," she said. "But it was really once I started meeting the patients as a clinical medical student that I realised how much more clinical medicine had to offer. I have learnt a lot from my patients over the years."

In fact, one of the reasons behind her choosing to specialise in haematology was that it offered a mix of clinical and laboratory work. She said: "Haematology is fascinating because it gives you the scope to meet patients and then carry out your own investigations, you don't have to rely on the findings of somebody else."

Her other haematology work includes being a clinical lecturer in the Institute of Child Health of the University of Liverpool, where she takes an active part in teaching clinical medical students, and she is the co-ordinator for a national audit programme of a childhood bruising disorder called ITP.

It is only relatively recently - in 1987 - that Dr Bolton-Maggs had the chance to move into paediatric haematology. During 1979 to 1991 she trained part-time while raising her own two children. "When training in haematology, you have to gain experience in paediatric haematology. I found I liked it so much that I wanted to stay in it."

The role of Haemophilia Centre director is not always easy. "It brings with it some difficult managerial responsibilities. No, the part that I most enjoy is helping the patients and their families."

There are about 100 patients at the Alder Hey Centre with mild bleeding disorders and around 30 with severe deficiencies. There is one clinical nurse specialist post that is job shared between two nurses. The centre also has a part-time nurse practitioner as well as input from a social worker, physiotherapist and other consultant experts, including an orthopaedic surgeon, a dentist and, more recently, a hepatologist for problems associated with hepatitis C. There is also a secretary who helps keep Dr Bolton-Maggs organised.

As part of a group of UK Centre directors, Dr Bolton-Maggs has recently contributed to guidelines on von Willebrand Disease. These are the work of the of the 'VWD working party' and are due to be published in September. The guidelines will include a section of information for patients and parents.

Dr Bolton-Maggs' husband, Ben, is a consultant orthopaedic surgeon based at a split site NHS trust - Whiston and St Helens.

They met at university and married in the early '70s. They have two sons, Emlyn, 17, who has designs on a career in engineering or physics, and Mark, 14, who will 'probably do something scientific'. "They have no interest in following us into medicine," Dr Bolton-Maggs said. "They think we work too hard."

PIONEERING HAEMOPHILIA B TREATMENT

A person with haemophilia B was treated with recombinant factor IX at the Royal Free Hospital in June - the first person in Europe to be treated with recombinant factor IX.

The synthetic version of factor IX has been developed by an American Company, the Genetics Institute, and clinical trials are underway in Belgium, France, Germany, America and the UK.

Dr John Pasi of the Royal Free who is looking after the person being treated with the recombinant product said: "The development of recombinant factor IX opens up avenues of treatment for people with haemophilia B with reduced risk. I'm delighted that our centre is taking part in the world's first treatment of its kind."

Treatment with synthetic or recombinant clotting factors avoids the problem of transmitting human viruses, because human blood is not required in its manufacture. It is a very stable product, enabling operations to be performed with constant infusion.

CAN YOU HELP

The Society has been contacted by the mother of a five-year-old boy with factor IX deficiency and inhibitors who is looking for someone in a similar position to herself. The little boy has severe factor IX deficiency, but doesn't have many bleeds. His mother is not sure whether or not to have a portacath fitted. She would very much like to speak to another mother who has been through a similar situation. If you can help, please contact the national office on 0171 928 2020 and we will put you in touch.

BIRTHS MARRIAGES AND DEATHS

If you would like the birth, marriage or death of a loved on to be recorded in the Bulletin write to: Andy Cowe, Editor, The Bulletin, The Haemophilia Society, 123 Westminster Bridge Road, London SE1 7HR. Give full details of the birth, marriage or death and also include a day time telephone number where you can be contacted.Please note that entries should be made as brief as possible, and in general should not exceed 100 words.

BIRTHS

A son, GRO-A o Mr and Mrs GRO-A and a brother to GRO-A, born on the GRO-A at Lewisham Hospital.

DEATHS

GRO-A . Died 9 July 1995 aged 31. GRO-A was a very popular darts player who won numerous trophies over the years. He fought hard to maintain his independence despite his failing health and will be loved and remembered by so many for his unfailing sense of humour, courage and fortitude. GRO-A 's death has left a large void in the lives of his parents GRO-A and GRO-A and his twin sisters GRO-A and GRO-A Our thanks to all staff at Lewisham Hospital who cared for him over the years.

GRO-A Died 10 May 1994 aged 35 GRO-A 's sudden and tragic death came as a surprise to his family and friends alike GRO-A s survived by his parents GRO-A and GRO-A, his sisters GRO-A and GRO-A and brothers GRO-A and GRO-A He also leaves behind his beloved GRO-A and children GRO-A and GRO-A His popularity at work, where he was a production manager, was shown by the shutting down of the factory for the day of his funeral and a memorial trophy being established at his workplace. The family sends thanks to the staff at Manchester Royal for their efforts on GRO-A behalf.

XXII INTERNATIONAL CONGRESS OF THE WORLD FEDERATION OF HEMOPHILIA

The XXII WFH World Congress will be held in the campus of University College, Dublin on June 23-28. The theme of the Congress will be "From Care to Cure". The Congress will include lectures and symposia on a number of of aspects of haemophilia care and there will be opportunities to meet and discuss haemophilia issues with experts as well as with other people with haemophilia from around the world.

As usual the Society will be sending a delegation to the Congress, but as it is happening so near to the UK it is an opportunity for people with haemophilia in the UK to attend and see for themselves what is happening in the world of haemophilia.

There will also be a youth meeting at the Congress, where one youth delegate nominated by each national haemophilia organisation will receive free registration including three nights accommodation and meals. The UK youth delegate has not yet been selected, so if you are interested, please contact the national office for more details.

For more information about the Congress, contact Haemophilia Conference 1996 Secretariat, c/o Conference Management Services, 26 Temple Lane, Dublin 2, Ireland. Tel: (+353-1) 679 7655.

CONTACT LIST FOR LOCAL GROUPS

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

ENGLAND

CAMBRIDGE & DISTRICT
Mrs Brenda Sharman
GRO-C
Suffolk
GRO-C

CORNWALL
Mrs Ivy Ovens
GRO-C
Cornwall
GRO-C

DERBY
Mr T A Harding
GRO-C
Staffs
GRO-C

HAMPSHIRE
Mrs M Clark
GRO-C
Hampshire
GRO-C

KENT
Mrs F Slade
GRO-C
Kent
GRO-

JERSEY
Mrs P Fosse
GRO-C
Jersey
GRO-C

LEICESTERSHIRE & RUTLAND
Mr Howard Tomkins
GRO-C
Leicester
GRO-C

LINCOLN & DISTRICT
GRO-A

MERSEYSIDE
Mr Simon Anakin
GRO-C
Merseyside
GRO-C

NORFOLK & NORWICH
Mr M Bush
GRO-C
Norwich
GRO-C

NORTHAMPTON
Mrs R Shaw
GRO-C
Northampton
GRO-C

NORTHERN
Mrs H E Pepper
GRO-C
Newcastle upon Tyne
GRO-C

NORTH WEST
Mrs N Guy
GRO-C
Lancs
GRO-C

NOTTINGHAM
Mr C Goddard
GRO-C
Nottingham
GRO-C

OXFORD
Mrs Mary Brooks
GRO-C
Oxford
GRO-C

SOUTHERN
Mrs M Haynes
GRO-C
Dorset
GRO-C

SOUTH ESSEX
Mrs M Baker
GRO-C
Essex
GRO-C

WALES

NORTH WALES
Mrs C Holliday
GRO-C
Clwyd
GRO-C

SOUTH WALES
Mr G Lewis
GRO-C
Cardiff
GRO-C

SCOTLAND

PERTH
Miss W McAughey
GRO-C
Perthshire
GRO-C

GRAMPIAN
Mrs C Robertson
GRO-C
Aberdeen
GRO-C

S E SCOTLAND
Mrs Carolyn McGimpsey
GRO-C
East Lothian
GRO-C

TAYSIDE
GRO-A

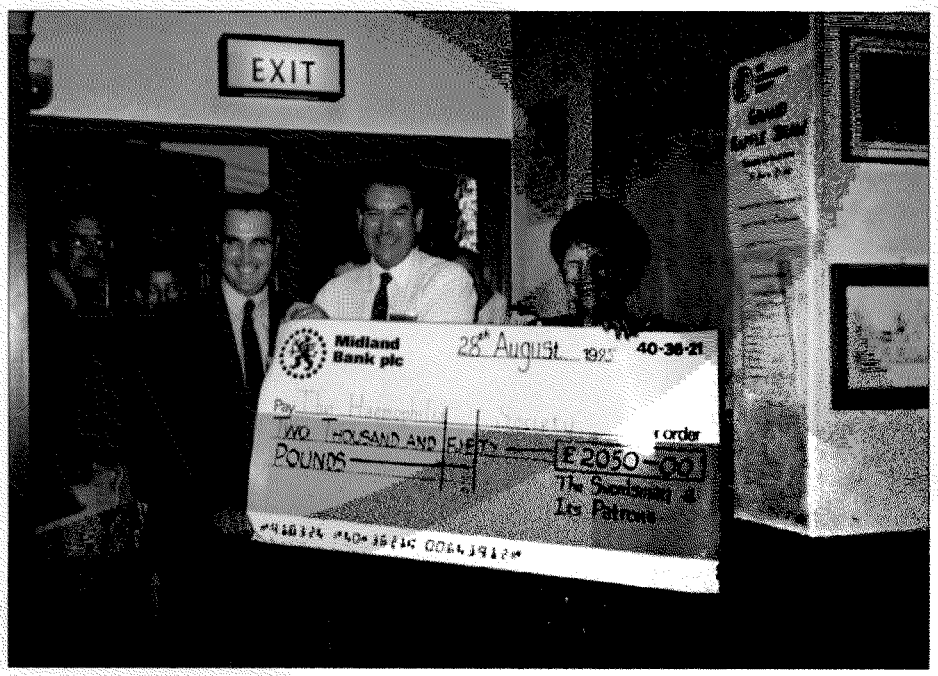
WEST OF SCOTLAND
Mr Phil Dolan
GRO-C
Glasgow
GRO-C

NORTHERN IRELAND

Mr S Graham
GRO-C
Belfast
GRO-C

A WEEKEND TO REMEMBER

Staff and regulars at the Swordsman's Arms in Stamford Bridge, York, helped to raise over £2000 over the August Bank Holiday weekend. There were a wide range of activities for the whole family to enjoy including a Quiz Night and Music Evening. Amongst the more unusual events were "thwack the rat", human fruit machines and landlord in the stocks! Our warm thanks go out to John and Gillian Saggers, Landlord and Landlady, and all the regulars for all their hard work, enthusiasm and generosity. A special thank you to Society member Ewan Thompson for helping to make the weekend such a resounding success. "In the seven years I have been fund raising for the Society I have never been involved in a better organised, attended or enjoyable event," said Ewan.



John and Gillian Saggers hand over the proceeds from the Swordsman's Arms charity weekend.

SEEING RED AT CENTERPARCS

Visitors to CenterParc saw red this summer. They were faced with a sea of children in red Kent Group T-shirts who were all there on a special family holiday arranged by the Group.

BAXTER REACH THE TOP

Baxter Employees Reach the Summit for Society

An intrepid team from Baxter Health Care successfully completed the "Three Peaks" challenge on June 23 in aid of the Society. The team achieved their goal of climbing Ben Nevis, Scafell Pike and Snowdon in just twenty-four hours with seconds to spare, raising over £5,200 in the process. An exhausted but elated team completed the descent of Snowdon just twenty seconds before the deadline.

One of the team organisers, Joanna Le Put commented: "All the months of hard work, training and preparation really paid off. The weather was excellent and we were pleased to be able to raise this amount for the Society."

The income from this event has made a welcome boost to our funds. Well done and thanks to everyone at Baxter who took part or contributed.

SOCIETY SERVICE OF THANKSGIVING

Our Annual Service of Thanksgiving in memory of those people with haemophilia who have died is being held on Saturday October 28th at 3pm in the Church of St Botolph Without, Bishopsgate, London. The service will be conducted by our Chairman the Rev Preb Alan Tanner.

The service is open to everyone who wishes to remember those who we have known and loved, worked beside, shared time with, those we have cared for as friends, family members, doctors, nurses, social workers or physiotherapists.

It is an occasion to which everyone is welcome - no one should feel that they cannot attend.

As has become our practice over the years, there will be a special act of remembrance when we place on the altar our own written thoughts about those we remember.

If you cannot attend, please send any thoughts or messages to us marked simply: "PRIVATE AND CONFIDENTIAL FOR OCTOBER 28". They will be passed to the Chairman only and he will make sure that all such messages are destroyed afterwards. Please do not enclose anything else in your envelope as we will not open it or read the contents.