Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392059

THE BULLETIN

Magazine of the Haemophilia Society

1998 ISSUE 4

CAMPAIGN UPDATE

by Karin Pappenheim, Chief Executive

The Society's two campaigns for recombinant and hepatitis C continue. Having achieved a breakthrough on recombinant earlier this year with the Government's announcement on provision for the under 16s and newly diagnosed, we will be pressing on with our campaign to make recombinant available for all. A survey is being carried out by the Society to find out about health authorities plans for next year, information which will be useful in the campaign. We also want to ensure recombinant factor IX is included in the provisions which apply to recombinant factor VIII at present.

On the hepatitis C front, the Society does not accept the Government has made the right decision, and we are calling for a public inquiry into the impact of the HCV infection on the haemophilia community. We have asked the Health Select Committee to take up the issue. Its chairman David Hinchliffe, Labour MP for Wakefield is known to be sympathetic, as are several other members of the committee. A mailing went out in November to all our supporting MPs urging them to keep backing the campaign, to ask Parliamentary Questions and as a result our supporters have put down an Early Day Motion urging Government to reverse its decision. On the press front, *Disability Times* carried a major feature on the campaign in November, and *Health Which?* has published a piece on hepatitis C, which will be helpful in raising public awareness of the virus.

What you can do:

- Keep up the pressure on your own MP - ask him or her to back our call for the Health Select Committee to hold an inquiry
- Join the HCV campaign supporters database at national office
- Raise the issue within any groups you are part of e.g. unions, other voluntary organisations, women's groups. Please let the Society know if you are a member of a union or have any contacts among high ranking clergy.
- HCV Campaign information available from national office from Sue Rocks or Lucy McGrath.

Sister Jill Smith, Dr Morag Chisholm and Dr Dma Choudhury say farewell having spent many years caring for people with haemophilia. We would like to thank them for the commitment they have given to their patients at the Southampton Haemophilia Centre.

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THE HAEMOPHILIA SOCIETY

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

We welcome reproduction of articles on the understanding that acknowledgement is made of **The Bulletin** as source.

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Many thanks to:

Grifols • Bayer • Baxter Healthcare • Centeon • Ipsen

CONTACT LIST FOR GROUPS

In order to establish contact with your local Group you should write in the first instance to the national office.
We have Groups in the following areas.

ENGLAND

CAMBRIDGESHIRE & DISTRICT • CORNWALL • HAMPSHIRE
KENT • LEICESTERSHIRE & RUTLAND • LINCOLN & DISTRICT
NORFOLK & NORWICH • NORTHAMPTON • NORTHERN
NORTH WEST • NOTTINGHAM • OXFORD
SOUTHERN • SOUTH ESSEX • YORKSHIRE

WALES

NORTH WALES • SOUTH WALES

SCOTLAND

PERTH • GRAMPIAN • TAYSIDE • WEST OF SCOTLAND

NORTHERN IRELAND

Northern Ireland Group

SPECIAL INTEREST

Birchgrove Group • Manor House Group

SERVICES AVAILABLE FROM THE SOCIETY

- General information about haemophilia and related bleeding disorders
- Information about Social Security benefits
- Information, advice and support on hepatitis and HIV
- Information for parents of newly-diagnosed children
- Parent support network
- Hardship grants
- Centeon Call pager service
- Caravan holidays in the UK
- Adventure holidays and weekends for children
- Fundraising support
- Assistance with media enquiries
- Information on treatments
- Travel advice and travel insurance advice
- Haemophilia Days and Family Days
- One-off meetings on specific issues, such as hepatitis
- Hepatitis C Support Network
- C. Issues
- Von Willebrands Support Network
- Mild and moderate haemophilia support contacts

For more information about any of the above services, please contact the national office.
Full details of our services are also available on our web site: www.haemophilia.org.uk

Editorial

by Dr David Evans

Again we have received more articles than we can publish. This is a really positive sign of the interest in *The Bulletin* from the whole haemophilia community. I wish we had space to publish all these contributions but some have had to be held over for another issue. However, this edition includes a larger selection of readers' letters, because it is important for us to know what you feel about the Society and what we are doing. So I hope that you will continue to write and send in your letters and articles.

The Chairman and Vice-Chairman of the Manor House Group have both written about Mary Clarke's appeal (in the Letters section of the last edition) for us all to work together as a united front. They both express the view that The Society is split into different groups and clearly feel that priorities of The Manor House Group differ from those of everyone else. In any Society there will always be people with different problems and different points of view; but we in the Haemophilia Society have to represent everyone's point of view. We are more likely to get what we want from the Government and others by speaking with one firm voice. The Manor House Group have told us what they need The Society to do; we have not yet achieved this, but we are and will continue to do our best for them and for all other members.

Previously we have had complaints that there was too much depressing news in *The Bulletin*, so it is a pleasant change to report some of the recent developments which should help people with haemophilia.

For those who are disabled the Government plans to ban automatic increases in the cost of insurance for people with a disability, and abolish the Benefit Integrity Project which was set up by the Conservatives.

For those with hepatitis C, the recent discovery of the way in which the hepatitis C virus finds its way into body cells should help the development of vaccines and drugs to treat the disease. If only someone could find away of getting into the pockets of the Government as well!

And for everyone, as a result of government action over problems like the disasters with children's heart surgery at Bristol, the doctors' organisations are going to take a tougher line to see that all doctors follow the best recommended practice. This should help us all.

Looking to the future

by Karin Pappenheim, Chief Executive

This is the time of year when plans are being finalised for the coming year. And 1999 looks set to be a very busy twelve months. We have a number of new projects and initiatives to be launched, all backed up with an intensive fundraising drive to provide the money to support this much needed work. Looking further ahead, the year 2000 will be our 50th anniversary and we want to use that opportunity to the full in fundraising and public relations terms. A 50th anniversary fundraising drive is planned, and we hope to set up a new Friends of the Haemophilia Society group to carry this forward.

Other objectives for 1999 are:

- To improve co-ordination and integration between national office and all the groups of the Society, both local and special interest

Please return your Local Group Forum Questionnaires. The information you provide will help us to reach these objectives

- To raise the profile of the Society, particularly our services amongst potential users and health professionals via a marketing/recruitment drive
- To improve the range and quality of our services, particularly in the light of feedback received through our members' survey, to meet the needs of people with haemophilia and other bleeding disorders
- To continue our campaigning for highest quality and safest treatment, specifically around provision of recombinant, and for Government recognition of the plight of those infected with HCV

Among the plans for new projects are initiatives targeting young people who are HCV or HIV infected to provide information and support directly for them and their carers. We also want to develop a programme of work addressing the needs of women with bleeding disorders, and to continue to provide support for carers in a variety of forms.

All this will involve a tremendous amount of hard work on the part of our national office staff team, together with the many loyal volunteers we rely on all over the country.

We're looking forward to a good 1999 and in the meantime may I wish all ***Bulletin*** readers a very happy Christmas and New Year.

Memberships, please...

Membership renewal letters are now going out; it costs just $10 a year, and in return you receive four copies of ***The Bulletin***, full voting rights in Board elections, important information about treatment issues and Society activities and opportunities to meet others through our events and meetings. And remember that The Haemophilia Society relies on income from our members as part of our funding base – so by paying your $10 membership you are helping us to help all people with haemophilia and related bleeding disorders.

Christmas Office Hours: The Haemophilia Society office will close at 3pm Thurs 24th Dec and reopen Mon 4th Jan 1999 at 9am.

We would like to thank everyone for supporting the Society over the last year.

Wishing you a Merry Christmas
and a Happy New Year
from all the staff at the National Office.

Gene Therapy for Haemophilia

by Dr K.J. Pasi

Dr K.J. Pasi is a Consultant in the Haemophilia Centre at the Royal Free Hospital and School of Medicine, London.

Gene therapy is often talked about as the cure for haemophilia. Many people see it as the next big treatment advance in haemophilia. But what actually is gene therapy and how far away is it in the future? Will it be a cure? How does it work?

What is gene therapy?

Genes are the blueprints for the production of all proteins in the body. An abnormal or deficient gene leads to disease because there is either not enough protein or it is abnormal. Gene therapy is the introduction of genes into a cell, aiming to replace or add a normal version of an abnormal or deficient gene to that cell. In the case of haemophilia this is an abnormal factor VIII or factor IX gene. Most gene therapy in haemophilia is gene addition rather than replacement. That is to say a normal copy of the abnormal gene is added to the cell rather than swapping the abnormal gene for a normal one. Gene replacement, swapping a normal gene for an abnormal gene, is theoretically feasible but remains a long way in the future. With present technology gene therapy cannot be a true cure for haemophilia, but an alternative and hopefully better longer lasting treatment than present factor replacement therapy.

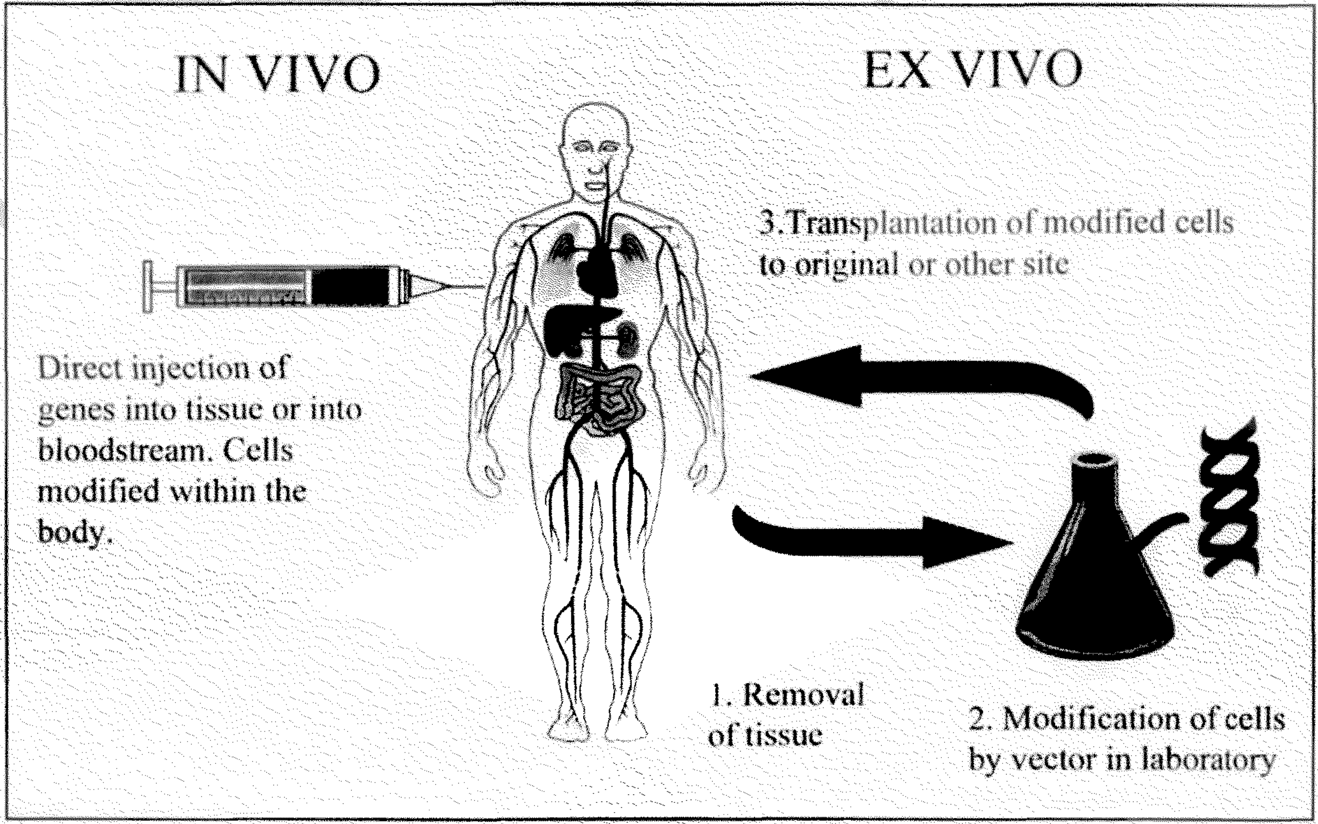
Why is haemophilia a big target for gene therapy?

We do, after all, have good treatment in recombinant factor VIII and shortly recombinant factor IX. Haemophilia is a major target for gene therapy because it is a chronic, disabling disorder that is due to a defect in just one single gene. Hence it is simpler, in concept, to correct compared to diseases that involve multiple gene problems. Replacement treatments are expensive and despite safe products being available there remains an ever-present concern about potential risk. Furthermore, in 80% of the world, treatment is not available and gene therapy may offer the only hope of practical treatment for severe haemophilia. Lastly and importantly only a small rise in factor levels to 5-10% of normal would he needed to protect against spontaneous bleeding. We do not have to correct haemophilia completely to make life a lot better.

Today the goal for haemophilia is to develop a treatment, for patients with severe haemophilia that can be given once or twice per year by injection. This 'gene therapy drug' that would raise factor levels to 10% or sufficient to stop spontaneous bleeding episodes. This is the target for scientists working on haemophilia gene therapy.

How can we put genes into cells?

Genes can be put into cells by various systems, by directly injecting them, or getting them into cells using modified



viruses. Viruses naturally move genes and DNA as part of their lifestyle. Viruses to put genes into cells are called vectors. They include retroviruses, adenoviruses (common cold virus) and adeno-associated viruses (AAV). Genes can be introduced into cells either outside the body (ex-vivo) or within the body (in-vivo), see figure. Both systems are being explored but obviously in-vivo systems would be better in the long run.

How far have we got?

Retroviral vectors have been commonly used by ex-vivo gene therapy but in haemophilia, models have not been particularly successful. Adenovirus has been extensively explored and initially gave encouraging results. However as would be expected from a common cold virus there is an immune response to the adenovirus and the immune system kills the cells that have had the clotting Factor gene added to them by the virus. This means that these cells only produce factor IX or factor VIII for limited time. In addition because of antibodies developing to the adenovirus it is difficult to reuse them to introduce more clotting factor genes. Much work is being performed to modify adenovirus to reduce the immune response.

AAV has recently been shown to transfer factor IX genes efficiently and lead to good production of factor IX. It is the most promising system for haemophilia B at present. AAV based gene therapy can correct bleeding problems in small animals with haemophilia B and is now being tested in dogs that also have haemophilia B.

Gene therapy for haemophilia A is more complex than haemophilia B. This is because the factor VIII gene is far more complicated than the factor IX gene. As a result haemophilia A gene therapy has progressed less than haemophilia B, although results overall are still encouraging.

When will gene therapy become available?

There is a widespread view that we will probably see the first trials to look at safety in humans within two years. This will probably be with an AAV and factor IX based approach for patients with severe haemophilia B. This does, of course, assume that the present studies in dogs are successful and the system proves to be safe. Haemophilia A is still a considerable way off.

A second question is who will be eligible to take part in the first clinical trials. This is not yet decided and there are many different views on which patients may be able to volunteer for such studies.

The realistic prospects for gene therapy are certainly getting better. There remain a number of research areas and questions that need to be answered before gene therapy can become a reality, but the picture is getting progressively clearer. However, it is very important that we remember that any gene therapy treatment must be defined to be safe and that it is feasible for human use. ●

This article is modified from one written by Dr. Pasi for Centeon News and is reprinted with their permission.

Summer Holiday Camps

by David Evans

It never rains but it pours. For this edition, *The Bulletin* has received reports of three activity holidays. Unfortunately, we do not have space to publish them all, and I can only give a brief report of each.

Dr Korn and later Dr Gozzard have been the medicos at the North Wales adventure holidays for the past 18 years, the last 10 of which have taken place at the Plas Menai Activity Centre. They have had the warm support of Carol Holliday and the North Wales Group together with local doctors and nurses. The doctors have written about the exciting and challenging courses available there. Boys and girls can go sailing, windsurfing, canoeing, rock climbing, abseiling, gorge walking, or try hill-walking, beach games, driving power boats, orienteering, barbecuing as well as more usual organised games. A wonderful opportunity for young people to try a selection of adventures.

Children from other European countries have been to North Wales, and this year Carol Holliday was able to go with four boys with mild haemophilia to a Swedish summer camp on the Baltic Sea, north of Stockholm. Fewer activities were available than at Plas Menai, but some children were able to go to an island by canoe and stay the night there. Everyone was very hospitable and helpful.

Brenda Buzzard from the Newcastle Centre has told us about the sports training camp in Italy, Il Giocco Regazzi, where she and Kim Johnson took five boys with haemophilia. Newcastle has previously organised Italian trips but this was at a new site. The boys did a range of sporting activities, and came back with medals for the mini-marathon, tennis, distance throw, and long jump. It is planned to make this a regular international camp for boys and girls with bleeding disorders.

We must be grateful that so many people take so much trouble to organise these courses and camps. I know how much young people, particularly those with long-term problems such as haemophilia, benefit from going to them. We are also grateful to those individual donors, corporate and trust supporters who have helped The Haemophilia Society to fund these activities. Each year money has to be raised "to make it happen". Long may they continue.

If you would like to know more please contact:

North Wales: Dr D I Gozzard Tel: GRO-C
Craigdulas, Rhyd-y-foel Road, Llanddulas,
Abergele, Clwyd LL2 8EG

North Wales: Carol Holliday Tel: GRO-C
84 Bastion Gardens, Prestatyn, Clwyd LL19 7LU

Italy: Brenda Buzzard Tel: GRO-C
The Haemophilia Centre, Royal Victoria,
Newcastle Upon Tyne NE1 4LP

The Bristol Family Day

by Joan Doyle, Services Co-ordinator & Benefits Advisor

The day began with a welcome speech from Karin Pappenheim. She spoke of the Society's aims for the year ahead and long-term goals for the future. This was followed with an excellent presentation titled 'Prophylaxis and Port-A-Caths' by Dr Peter Collins. He clearly described how prophylaxis should begin as soon as possible. This prevents joint problems and enables children to live a full and active life. There have been many concerns regarding Port-a-Caths and the risk of infection. Dr Collins explained exactly how the port was fitted and the techniques to prevent infection.

The workshops that took place during the day covered many issues for people with haemophilia and their families. 'Women who are Carriers' covered issues ranging from tests for carrier status and at what age this should be carried out, prenatal testing, whether to have children, birth and personal experiences of a mother of a child with haemophilia. 'Fathers' also had the opportunity to discuss their experiences. This workshop allowed dads to freely discuss their feelings and share their experiences, for the first time in many cases. *(See Fathers' Workshop on page 15.)*

Sport has become a very topical issue. Parents realise the benefits of regular exercise for a child with haemophilia. Parents were advised on sport and protective clothing, footwear and items such as shin pads and also about the dangers of being over protective with their children.

Home treatment and Schools are as ever very popular workshops. There are still obstacles to overcome with home treatment such as anxiety of giving an injection and parents fear of hurting their child. It is through parents sharing experiences at events like this that these fears can be overcome.

The von Willebrand's Disease workshop covered medical and emotional issues. The Society was asked to continue to raise awareness about vWD.

Parents were able to relax, participate if they wished, or listen and enjoy the experience while their children were enjoying a trip to Bristol Zoo and The Exploratory, an interactive science museum. Feedback from the day helps the Society to plan future events.

Thank you to everyone who helped to make the day a success. ●

What the children got up to...

While the parents attended the conference the children enjoyed themselves…

A creche was provided for the younger children who enjoyed many games and activities.


GRO-A

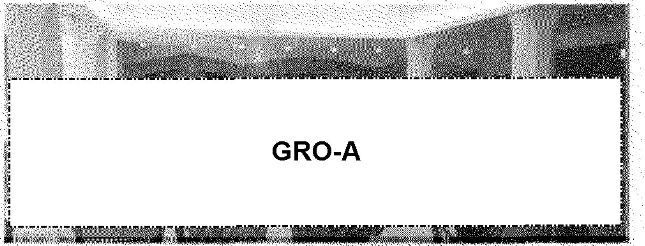
For the older children there was a trip to Bristol Zoo Gardens in the morning to see all kinds of animals, insects and reptiles. In the afternoon there was a visit to 'The Exploratory', a hands-on science centre with many fascinating experiments that the children could perform themselves.

The Belfast Haemophilia Day

by Lucy McGrath

This took place in November at a hotel just outside Belfast. Over 80 adults and 30 children attended the day which was a great success with workshops on a variety of subjects from von Willebrand's Disease to Living with Hepatitis C.

We were given a wonderful welcome by the local Northern Ireland Group, and special thanks must go to this group, particularly Shaw Graham, Cathy Kerr and Gordon Clarke for their help in organising the day, and their warm hospitality. Thanks also to the workshop facilitators who shared their knowledge and experience with us.


GRO-A


GRO-A

A final thank you to Bayer who sponsored this event. ●

RED RIBBON PAGE

Feedback from *The Treatments and Alternatives* Conference

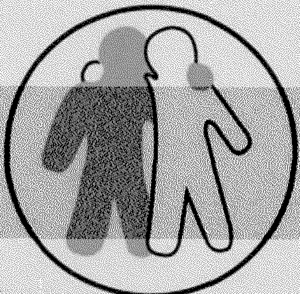
by Steve Fouch, HIV Worker

At the end of July, about sixty people gathered in Bath for the National Birchgrove conference. Nigel Hughes, Clinical Nurse Specialist in HIV & Virology at Mid Kent Healthcare Trust spoke on the health and treatment issues around co-infection with HIV and hepatitis C. Raffi Babakhanian of the AIDS Treatment Project in London hosted a question and answer session on the latest developments in HIV therapy hot off the presses of World HIV Conference in Geneva. Both sessions were well presented and well received.

Members were able to meet each other and staff from the Society and the MacFarlane Trust, and there were a couple of useful question and answer sessions that gave us a chance to address issues of concern.

The Birchgrove Group, the MacFarlane Trust and the Society hope to run a number of other events in the future for those who are co-infected, and their families. If you have any suggestions on what you would like to see in future events, please call, write or e-mail Steve Fouch at the national office. If you would like a report on the events, contact Steve Fouch or The National Birchgrove Group on 01222 373560.

APPEAL



We have recently been contacted by a young man with haemophilia and HIV infection being treated in London. He is from the Middle East, and has, until recently, been funded by his own government to receive Factor VIII treatment here as none is available in his own country. However, this has now stopped.

He is hoping to study here in the UK, and in order to remain healthy needs access to both Factor VIII and HIV treatments. To stay here he has to raise money. In particular he is looking for financial support with his course fees, accommodation and living costs. If you can help this young man remain in the UK for the next couple of years, it would make a great difference to him and his family.

If you would like to give something, anything at all, toward his cause, please send contributions as cheques or postal orders made payable to ***The Haemophilia Society*** to *Steven Fouch, HIV Development Worker* at the national office.

The MacFarlane Trust Review

Over the past three months, the MacFarlane Trust has been undertaking a review of the needs of its registrants. This is both to present the case to the Department of Health for continued funding for the Trust, and to identify the needs of its registrants to help it, and other organisations to be more responsive.

The Society has been involved in the development of the Review, and in some of the research that has gone on, including one-to-one interviews of members and supporting focus groups being held in different parts of the country.

The report is being written up as you read this, and the Trust will be notifying registrants of the findings. It is hoped that by listening to your needs more closely, both the Society, and the Trust can be more supportive and responsive.

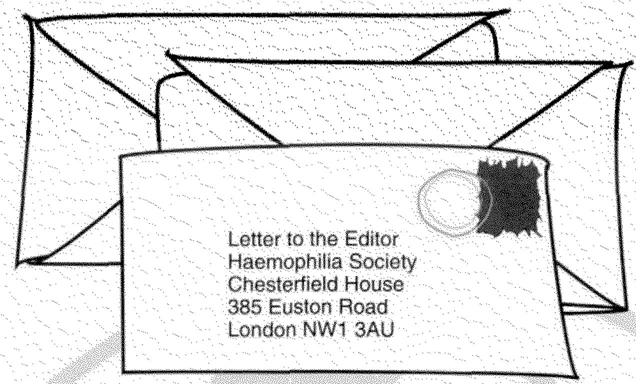
If you have any questions, please contact Steve Fouch or the MacFarlane Trust on 0171 233 0342.

Information on Treatments

A number of people have called in recently with concerns about the side effects of combination therapy, or how and when to start. Of course, the best people to discuss this with are your centre staff, but there are plenty of other sources of information that are worth checking out.

If you are having concerns over HIV therapy, and would like more information on the treatments available, and the side effects and problems they may be causing, please give me a ring at the Society Office. Alternatively, you can contact ATP on 0645 470047, or the THT Helpline on 0171 242 1010.

Letters to the Editor



The Chairman of the Tayside Group writes regarding GRO-A' article in Issue no.2 of* The Bulletin *this year.

"Although we do note that the author, GRO-A has used caustic humour in writing this piece, we consider that the content is inappropriate for inclusion in the official Society publication. In particular, the reference to being "embarrassed dropping bloody syringes on the floor of a train when wrestling a book out of my rucksack" is irresponsible and likely to present an inapt influence to impressionable young people.

As the author is an employee of the Society care should be taken to be responsible and not to imply countenance of any actions which are contrary to good practice in the administration of treatment and disposal of used equipment. We are disappointed that the article does not uphold the normally high standard of content of ***The Bulletin***."

***Editors Reply:* I agree with you that used syringes should not be allowed to drop on the floor of trains; however, I am sure GRO-A did not intend to encourage others to follow poor practice, and I do not think that something like this is likely to lead to other young persons with haemophilia doing the same. I am sure that GRO-A made the comments in a light-hearted attempt to describe the problems of travelling by train, where facilities for disposing of used syringes are difficult and sometimes impossible to find, and did not intend to set a bad example.**

Ante-Natal Tests

I was rather dismayed when I read GRO-A's article in the last issue. I know her article is written from the heart, but I was concerned about the effect it may have had on other parents, or would-be parents. It gives the impression that ante-natal testing is always poorly organised, highly 'risky' and generally inaccurate. In fact, the article contains very little accurate information about ante-natal testing at all so the title is slightly misleading.

Perhaps it would have been useful to print an article to redress the balance by providing factual information about the tests available in pregnancy and information about the genetic work that ideally should be done before a pregnancy is embarked upon.

Although I appreciate that articles written by real people about themselves and their lives with haemophilia are interesting and can provide valuable learning and support tools for other members, I feel that we do no service to the haemophilia community by providing them with limited and emotionally charged information.

Angela Westoby,
Clinical Nurse Specialist,
Paediatric Haematology,
St James's University Hospital

***Editor's Comment:* I picked this article because I believe women whose children have haemophilia will appreciate GRO-A's remarks. I consider it important that members are able to express their feelings in The Bulletin. As members frequently request more information and discussion of issues for carriers, we felt Mrs GRO-A's article added a very strong personal view. I agree that a follow up article giving factual information on ante-natal testing would be equally useful in a future issue.**

Obituary Note

In ***The Bulletin*** Issue 3, I noticed the 'Letters to the Editor' section. I haven't noticed it before and was pleased to see its inclusion.

When you mention the death of someone with haemophilia in the obituary section it would be helpful if the reason for their death were mentioned. Was their death related to a serious bleed or was their death completely unrelated? This is a sensitive issue, but as a haemophiliac myself I would find it useful.

GRO-A

***Editor's Reply:* So would I, but we do consider the relatives' feelings too.**

Split Society?

I would like to respond to the article by Mary Clarke, speaking in her role as Chair of the Hampshire Group, in ***The Bulletin*** Issue 3. She is concerned that the Society will divide into different groups. I must ask, is she living in the clouds? The Society is already split into several groups: we have haemophiliacs who have received a very derisory payment for being infected with HIV. We have young people who will be receiving recombinant products now coming on line, as they should. What have the people of my own generation been given? Absolutely nothing.

Since ***The Bulletin*** was printed I have received a number of phone calls asking me if this is the same Mary Clarke that sits on the board of Directors. If it is, we do not hold out any hope for the hepatitis C campaign.

I do not wish to appear callous or unsympathetic but Mary Clarke should keep her upsetting remarks to herself.

Finally, David Evans; in his Editorial stated that the HCV campaign has highlighted the need for better treatment for hepatitis patients. This lesson should have been learnt from the HIV campaign and not as an afterthought.

Stan Cockburn,
Chair,
Manor House Group

Editors Reply: **We need to help everyone with haemophilia. All those I speak to agree that we must continue the HCV campaign, and we shall. However, I would like to see all of us helping each other, and not just following our own particular needs.** *(See Editorial, page 3.)*

Mrs Clarke's letter contained a lot of subliminal messages and, I feel, patronising remarks. I would have preferred her to say what she really means. I too am privileged to belong to a particular group which is more supportive and united than any other I have experienced. The MHG are my family – in that they probably know me better than some of my relatives. Clouds do have silver linings. Without Hep C I would perhaps not have found such wonderful friends. However, whilst I have to live with 'these cruel burdens' I will not accept or condone them.

Wake up Mrs Clarke!! The Haemophilia community has been divided ever since some people received viral infections through their contaminated treatment. We shall continue to be divided until we can secure safe treatment for all, and until there is some recognition by the Government that they have a moral obligation to us.

We must move forward with the issues that affect all of us and I would echo Mrs Clarke's question: "Is the Society catering for these people?" As a Trustee of the Society, Mrs Clarke should know the answer.

Mrs Clarke is partially correct. There is a small minority who are virus free and they are now hopefully receiving recombinant factor. This small minority is also divided. recombinant factor IX is not available and the prospects for its future production do not look promising.

Whether we like it or not, we are bogged down by current concerns, yet for many it is a case of life and death. There have been far too many mistakes made at the expense of haemophiliacs and we need to shout about it. History has a habit of repeating itself.

[redacted]
Vice Chair
Manor House Group

I read with interest the letter from Mary Clarke, Hampshire Groups, Chairperson (***The Bulletin***, Issue 3). It inspired me to write and say thanks for the contents. I have been married for 30 years to a man with haemophilia [redacted] is now 63 and one of the few haemophiliacs who did not contract HIV. He has now been told he is HCV positive, but up to now has no ill health. I feel this letter from Mary Clarke points to the fact that people like [redacted] have been forgotten. We feel guilty that he ONLY suffers so far from bleeds. He has had to have two knee replacements recently, which has set up inhibitors to his usual treatment.

We have been members of the Society for many years. There must be many other haemophiliacs like [redacted] who feel they cannot approach the Society because they ONLY have haemophilia. I hope you can redress this situation, because that is why the Society was formed, to help everyone.

Yours sincerely
[redacted] *(Mrs),*
Kenilworth

Can anyone help?

A parent of a child with Haemophilia B has contacted us about a long standing inhibitor to factor IX. Immune tolerance therapy has been suggested via a Port-a-Cath to combat the inhibitor. The parent would like to talk with any other parent of a child with Haemophilia B who has faced a similar difficulty. Please call Pete on [redacted] if you can help.

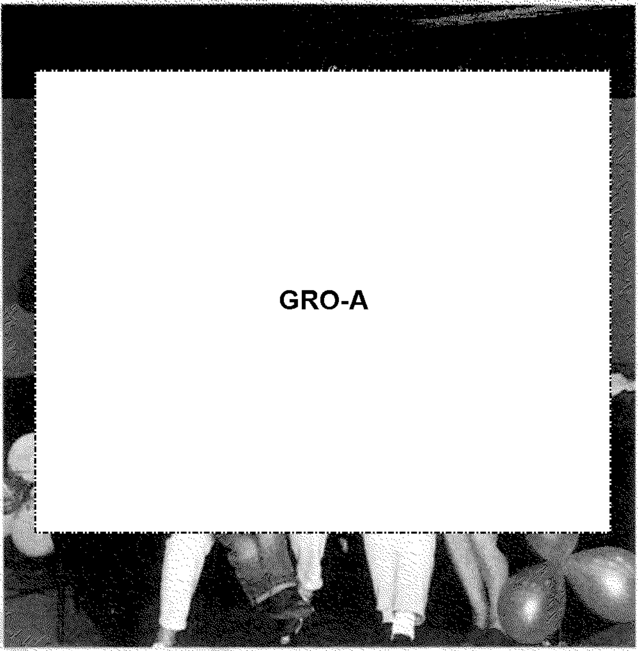
Northampton & District Group of The Haemophilia Society

by Liz Rizzuto

The Northampton & District Group of the Haemophilia Society was set up some years ago as a support group. Primarily these days their function is to fund-raise. In the past year the Northampton Group has raised in excess of £5,000. A spring dance with the Johnny Harris Big Band made an impressive £2,071.

The committee members would like to thank all those like Mrs Slasberg who give up their time and organise their own fund-raising activities. Future planned events will include a supper dance with Fynnius Fogg and another evening with the Johnny Harris Big Band (April 17 1999). The Kingsthorpe Golf Club has taken the local group on as their Charitable Cause for the next two years.

The funds raised are used to help those with haemophilia and their families, including a motorised scooter for one of their members, and items and pay for the upkeep of the caravan in Hemsby. Where possible, help is also given to those who are not members of the Group.



GRO-A

Members of the Northampton and District Group

TTV – a new virus

by David Evans

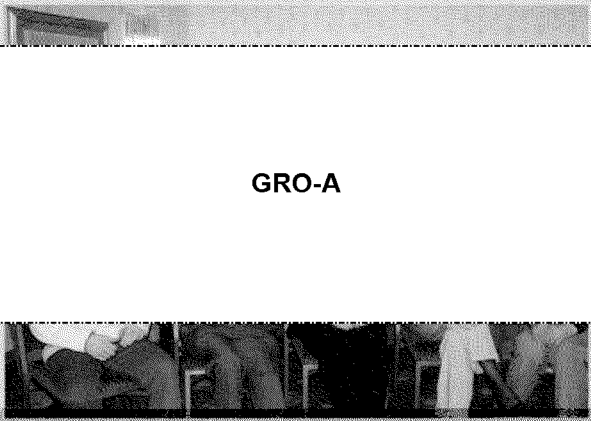
Scientists in Japan last year reported a new virus which they called TTV– transfusion-transmitted virus. It is very small, like parvovirus, and can be transmitted by blood and blood products. It has now been recognised in people all round the world, including the UK, and in some countries over half the population appears to have been infected. Here only about 1 in 50 seem have been infected, and few have had any problems. However, it has been associated with changes in liver function tests, and with the rare case of acute liver failure.

It has been found in clotting factor concentrates. Heat treatment appears to destroy it. It can still be detected after solvent-detergent treatment, but its infectivity seems to be inactivated.

These are early days, but at present no-one really knows if it causes long-term liver disease. Present evidence suggests that this is unlikely, and that it is not a serious health problem. We really need to know a lot more about this virus before we can make any firm remarks about it; but we felt that members would prefer to hear about it earlier, rather than later, We shall keep you informed as news comes through.

Meanwhile, this re-enforces our opinion that recombinants are the only safe clotting factor concentrates, and we are renewing our requests to the authorities to make recombinant factors available to all.

News from Scotland



GRO-A

Recently, with the knowledge that the new Scottish Parliament was going to have responsibility for health matters, the various Scottish Haemophilia Groups (Tayside, Grampian, South East Scotland and South West Scotland) have discussed their future.

There are various Scottish issues which need to be tackled in the light of political devolution taking place.

Memorial Services

There were two memorial services for those who have died as a result of HIV and/or hepatitis C in October. The first was in Birmingham at All Saints Church in King's Heath. This is the second year that they have held this event, and it was well attended by those in the West Midlands who have lost loved ones. The organisers hope to run this event again next year – watch this space for details.

The second service was held at St. Botolph without Bishopsgate in London, and included a dedication of the Book of Remembrance that will be kept in the church. It was a very well-attended and touching service.

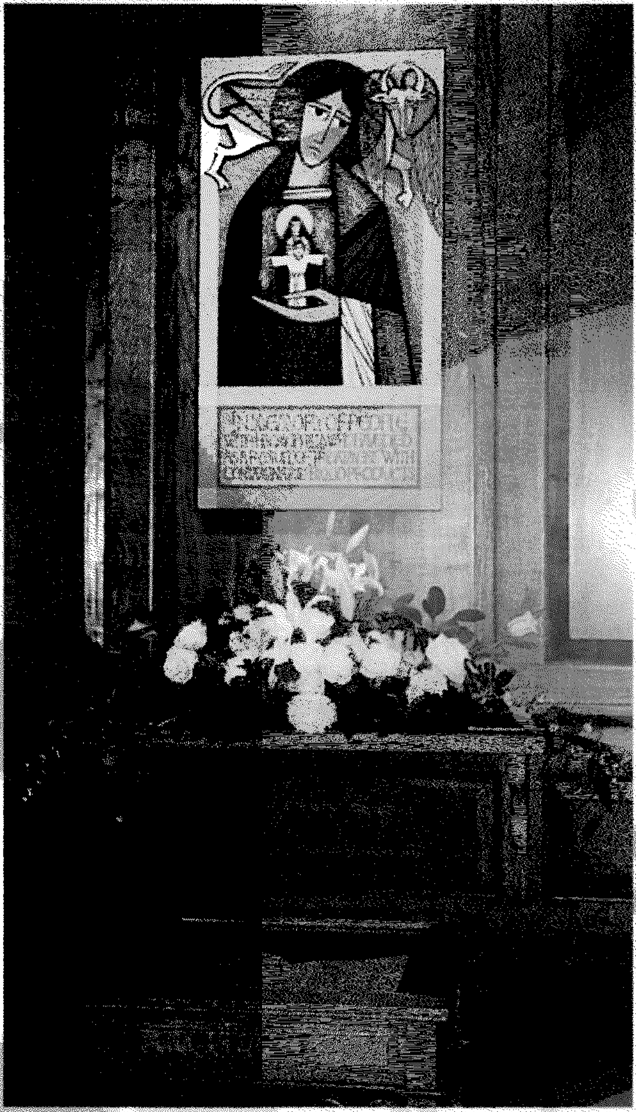
The Icon: In Loving Memory

The icon at St Botolph's Church (see picture, right) was specially commissioned as the central feature of the memorial for people with haemophilia who have died as a result of their treatment with contaminated blood products.

It depicts St. Luke the Physician, who was himself an icon painter, and shows him holding an icon of the Mother and Child. In the background is a winged ox, the evangelistic symbol of St. Luke. Behind the Mother and Child, in the traditional Greek lettering, is the title 'Jesus Christ the Victor'.

Below the icon is the Book of Remembrance which records the names of people who have died. The Book of Remembrance is open to the public when the church is open, although it is recommended that you ring first to check. Flowers may be placed at the Memorial and arrangements made for a candle to be lit and placed in the Church on the anniversary. If you wish to visit, or to have a name entered in the book, please contact Mary-Ann Tanner at St. Botolph without Bishopsgate, Bishopsgate, London EC2M 3CL, or telephone her on 0171 588 3388. Anyone who gave details of a loved one can get a copy of the entry in the book by contacting her.

St. Botolph without Bishopsgate is a parish church in the heart of the City of London and ministers to those who work in the Square Mile during the week. It is open from 8am to 5pm Monday to Friday, and has an 'Open Houses' weekend during September.



Everyone is welcome to visit the memorial, but please check first that the church will be open by telephoning the above number.

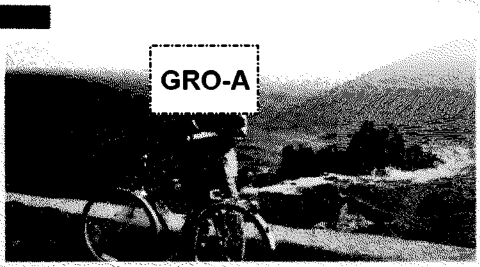
Obituary

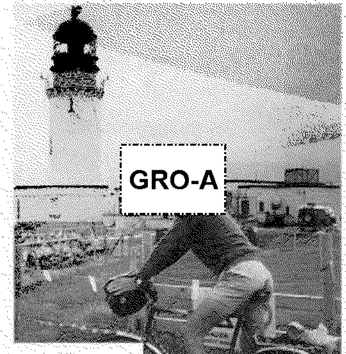
Alan Tanner's son GRO-A died on GRO-A. The text below was included in his funeral service to give a sense of the things which were important to GRO-A in his life.

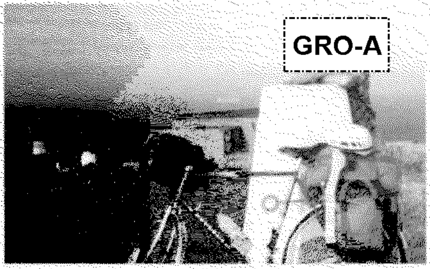
Mingus; Ignious; Bewitched; Don McCullin; Transformer; Exchange & Mart; Calcutta Cup; MS Dos; Rites of Spring; Blood Makes Noise; Bugatti; Merry Pranksters; Trane Babel 17; Mambo; Silver Surfer; Spanish Cabaret; Elliot Erwitt; Tropical Fish; Avedis; Zyldjian; The Rebel; Mandelbrot; Bacchus; Suicide Is Painless; Detroit Diesel; In The Middle Somewhat; Hang Ten; Cathy Gale; Body Electric; Butterfly; Twin Webbers; Ektachrome; Mistral; The Dogs of War; Gretsch; Rolling Reef; Mud, Blood, and The Colour of Grass; Beyond Colour; To Catch A Thief; Don't Look Now; Olympus; Chaos; Beano Chant; Ferrari; Ken Kesey; Doctor Strange; Beatnik; Bull Terriers; Ackrington Pals; The Old Man and the Sea; 1275cc; Half Life; Westwood; Night in Tunisia; Bucky Balls; 350GT Delaney; Balsa; The Salamander; Silicone; Accountess; Fractals; HBE; Uncertainty Principle; Nutcracker; Miles; Roferon; The Night Studio; Stüssy; Dancing Woo Lee Masters; Cumbia; Lemming; Bazooka Joe; Plasma Cutter; Zeitgeist; The Ashes; Popular Mechanics; Lotus 7.

Fundraising

GRO-A 's Four Corners Cycle Ride







GRO-A cycled around the four corners of the British GRO-A mainland starting on 16 April and ending after cycling 3,120 miles on 29 September.

"During 1998 I set myself the task of cycling around the British mainland from Dover to Land's End, Cape Wrath to John O' Groats. I successfully completed 3,120 miles of cycling. My aims were to visit as many friends and relatives as possible, and to raise money for the Haemophilia Society. Three of my brothers were born with haemophilia, of whom only one is now alive. I have been very encouraged by the generosity of the sponsorship and have raised £2300 to date!"

"As you can imagine, it was hard work at times, but it was also very worthwhile and enjoyable. I have been touched by the generosity of people who have sponsored me".

Well done GRO-A Your hard work will be a great help to the work of the Society.

Medite Half Marathon

GRO-A e and GRO-A GRO-A and GRO-A GRO-A all took part in the Medite Half Marathon on 11 October on behalf of the Haemophilia Society and raised a grand total of £515.00. Well done!

GRO-A 's horses

GRO-A is 35 and has severe haemophilia and hepatitis C. GRO-A In 1992 he rescued an abandoned Shetland pony and with tender care, love and affection, the pony has fully recovered and is now a star. He is called Teddy Bear, and has been on stage in a musical, had tea with old age pensioners, and been to countless children's birthday parties. Last Christmas he led the sponsored Bed Push through Oxford in aid of the Oxford Unit. He will also be appearing in the London Harness Parade in Battersea Park on Easter Monday.

GRO-A has also rescued a huge (872kg!) Clydesdale called Bob, who was about to be shot because he was difficult to manage. He has since won Supreme Champion at the Royal Show at Stoneleigh.

Bob and Teddy have worked with many television stars - Gladiators Hunter, Panther and Wolf, Eric Pollard of Emmerdale, Wendy Turner of Pet Rescue, Fred Dibnah and the Red Arrows. Next year they will be at the East of England Show, Herts County Show, Lambourn Nostalgia Show and East Challow.

GRO-A Teddy and Bob would be delighted to see people with haemophilia at any of these events. We wish them all the best of luck.

Society Friend

Thank you to a friend of the Haemophilia Society. Mr Frank Lenton has for a number of years been a keen supporter and fundraiser for the Society even though neither he nor his family have haemophilia. His interest stems from a friend whose family is affected by von Willebrand's Disease. This year he has nominated the Haemophilia Society to the Plymstock Branch of the Co-operative Society who generously agreed to support the Society in 1998. Mr GRO-A, Chairman of the Cornwall Group, is seen receiving the cheque of £330 from Mr John Wright, Director of Plymouth & South Devon Cooperative and Katrina Graves, Store Manageress.

Hucknall Road Runners

The 'Hucknall Road Runners' ran on behalf of the Haemophilia Society in their ninth annual 10K race, at the request of their Treasurer Sharon Severn, in August. They raised £250 for the Haemophilia Society.

Mini Triathlon raises £1,400

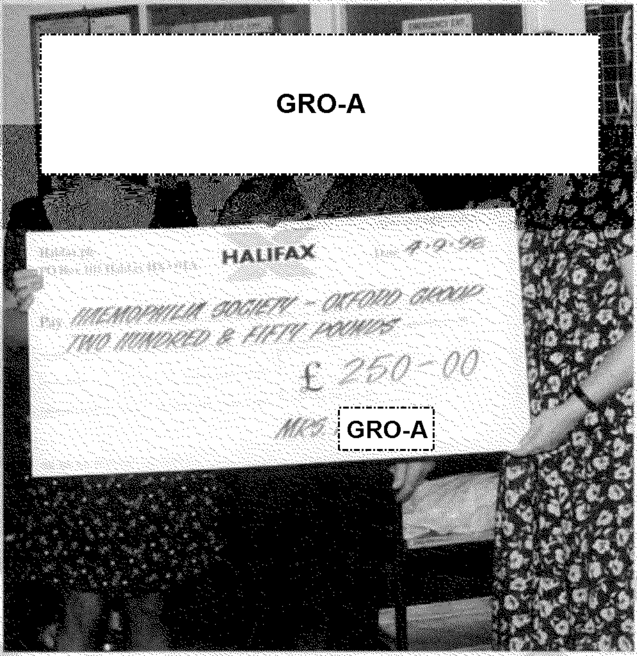
GRO-A and GRO-A have again worked hard in GRO-A their fundraising efforts and raised £1,400 for the Society. The event was held in their village during the summer, and they were lucky enough to have it on one of the only sunny days this year! Eight volunteers cycled 12 miles around the North Downs, and followed it with a three mile walk along with their families. The most physically demanding part of the event was a one hour swim in the local pool. GRO-A commented that "the initial joy of diving into a cool pool was soon overtaken by the slog that followed. Still we did it!" A big thank you goes to all those who volunteered and supported GRO-A and GRO-A

Disco Helps Fund Group Disney Trip

A disco in Newent has raised £250 towards a holiday-of-a-lifetime trip to Disney World for 15-20 boys in the Oxford area suffering from haemophilia.

Mary Brooks, specialist clinical nurse and secretary of The Haemophilia Society's Oxford Group, travelled to Newent to receive the contribution from GRO-A and GRO-A who raised the money at the Circle Club disco in July. GRO-A has three brothers and two nephews with haemophilia. The presentation took place at a 'Golden Oldies' event organised by Alan, steward of the Oxford Group, where a further £68 was raised.

Thanks again to all those who are helping to make the Disney World holiday a possibility for these deserving youngsters.



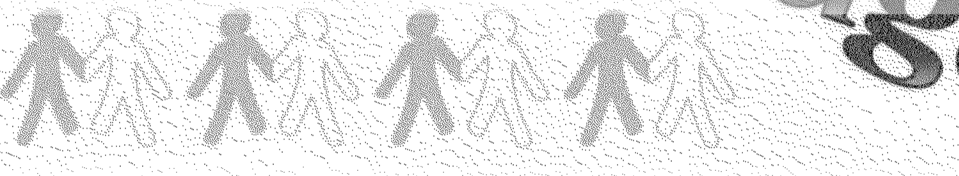
Poole Rotaract Club

Thank you to the Rotaract Club of Poole who have generously donated £70 to The Haemophilia Society which was collected by Southern Group Committee member GRO-A

Fundraising in 1999

Do you have any exciting ideas for fundraising in 1999? Please give Melissa a call on 0171 380 0600 to obtain a fundraising pack and discuss your ideas.

The Family Page



The Family Pages are compiled by Pete Brown, Children & Families Worker. Pete would like to hear from any parent, child or teenager who has articles or ideas for inclusion on these pages.

BRAINTEASER...

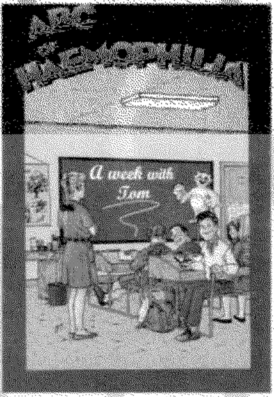
Large sailing ships of the 16th and 17th century were sailed by means of a complex series of ropes which made up the ship's rigging. If a rope snapped, it was expensive to replace so it was usually repaired by stretching the two broken ends and intertwining the strands (known as splicing).

- What modern saying comes from this that describes managing on a tight budget?

Send your answer in to Pete at the National Office and you could win a prize!

Why not send us your brainteasers and jokes?

The ABC of Haemophilia



The ABC of Haemophilia is an attractive and well presented package that will provide helpful information and advice to both adults and children alike. Young children will no doubt be eager to take ownership of the eye catching package and want to get started straight away. Older children will be able to understand in easy language the content. The book gives scope, and an ideal opportunity for parents to spend time to explain, where necessary, and expand on the story character, and their own learning experiences of living with haemophilia. Congratulations to everyone involved in the production, and the children who produced the drawings which added and brought life and meaning to the whole thing.

GRO-A

Parent of a 9 year old with severe haemophilia A.

The ABC of Haemophilia is available from Haemophilia Centres, The Haemophilia Society or direct from Baxter Healthcare. To order from Baxter phone 01635 206 265.

Lost & Found

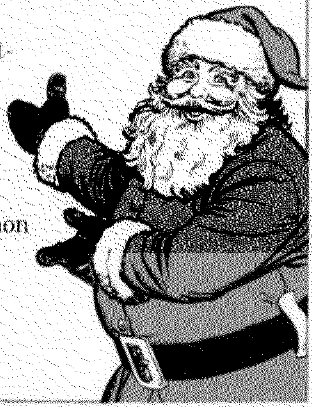
Did you leave a glasses-case behind at the Bristol Family Day? If so, contact Julie at the national office on 0171 380 0600.

THE CHRISTMAS QUIZ

Our Christmas quiz is for children and parents to have a go at together. See if you can win a prize! The first 5 correct entries each win a Haemophilia Society yo-yo or mouse mat. All correct entries will receive a Haemophilia Society enamel badge.

1. Where does Father Christmas come from and what two other names is he known by?
2. Name three of Father Christmas's reindeer.
3. Why is Haemophilia B also known as Christmas Disease?
4. Where is Christmas Island?
5. Who donates the Christmas tree that stands in London's Trafalgar Square every year?
6. *'On the twelfth day of Christmas*
   My true love gave to me...' What?
7. What happened on the twelfth day after Christmas?
8. What do people usually do on the twelfth night of Christmas?
9. How many Christmas card designs has The Haemophilia Society produced this year?
10. Complete the following:
    'Twas the night before Christmas,
    when all through the house
    not a creature was stirring,
    not even a...'
11. *'He had a broad face*
    and a little round belly
    that shook when he laughed...'
    What's the next line?
12. What is the all-time best-selling Christmas song?
13. Why is Christmas called Christmas?
14. What do all of these questions have in common (except this last one)?

Send your answers to Pete at the national office.



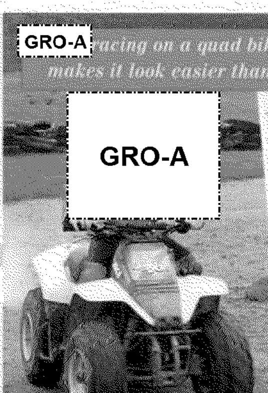
ADVENTURE WEEKEND REPORT

Boreatton Park in the Shropshire countryside was the setting for our second Adventure weekend which took place in September. This was where the pilot weekend took place last year and we were warmly welcomed back.

Activities included abseiling, kayak canoeing, archery, rifle shooting and a low level ropes course. There were also two new activities:– desk top publishing on computers in the new IT suite and the infamous 'zip-line' (aerial runway) which was a hair-raisingly fast slide down a steel wire attached between two trees, 500 metres apart.

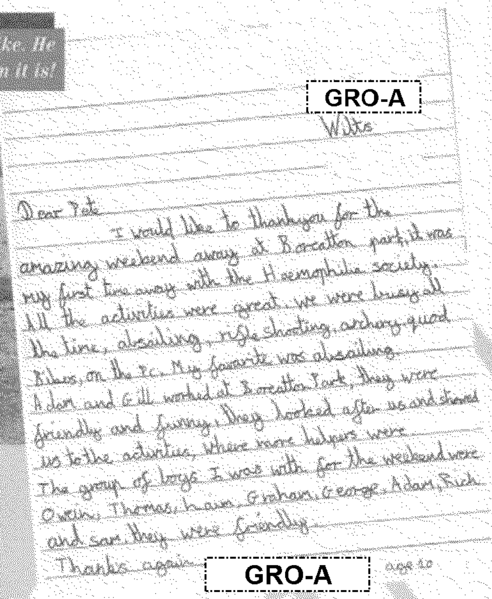
These short break weekends are proving to be very popular and provide a short break of lively activities for 8-13 year olds. We always take two haemophilia nurses for any treatment needed and we are careful to choose holiday organisations with properly trained staff and high safety standards.

Watch out for details of more weekends in 1999!



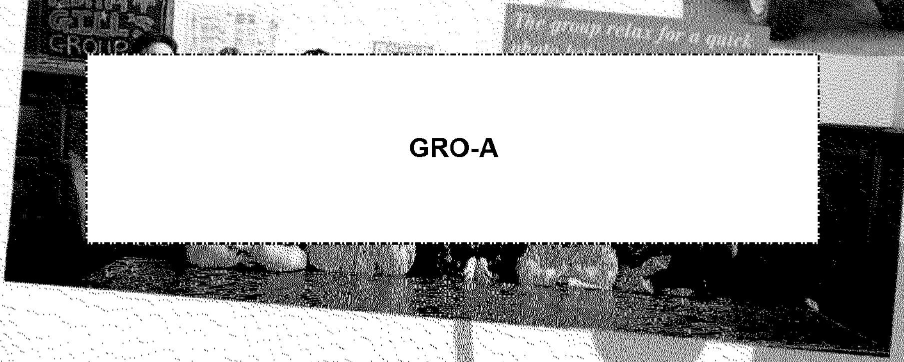
[redacted] racing on a quad bike. He makes it look easier than it is!

[redacted]



[redacted]
Wilts

Dear Pete
I would like to thankyou for the
amazing weekend away at Boreatton park, it was
my first time away with the Haemophilia society.
All the activities were great. we were busy all
the time, absailing, rifle shooting, archery, quad
bikes, on the PC. My favorite was absailing.
Adam and Gill worked at Boreatton Park, they were
friendly and funny, they looked after us and showed
us to the activities, where more helpers were.
The group of boys I was with for the weekend were
Owen, Thomas, Liam, Graham, George, Adam, Rich
and Sam they were friendly.
Thanks again [redacted] age 10



The group relax for a quick [redacted]

Thoughts on the Fathers' Workshop at the Bristol Family Day.

While eagerly searching through the new arrivals for a familiar face and reading everyone's name badge in case there was someone that I had missed, someone spotted my own badge that read: [redacted] *Parent of a child with haemophilia*. "Are you one of the speakers?" I was asked. Well, that was something I had not thought of! Was I a speaker? I hoped that the delegates booked into my workshop were not expecting a presentation. That was one thing they were definitely not going to get. As far as I was concerned it was their group and my purpose was simply to encourage them to open up and talk about whatever they wanted to. I now started to get concerned again. What if they all sat in silence? What if nobody turned up? Well, not to worry, it was a lovely hotel and I was enjoying the outing.

The room provided for the Fathers' Workshop was comfortably furnished and not too large, which was good to promote a friendly atmosphere. "The purpose of a Fathers' Workshop is to give the opportunity for fathers of children with bleeding disorders to get together and talk through the many issues that are particular to them. The main difference between this and other workshops is that I am not a healthcare professional. I too am a parent (hence the title on my badge). My function is neither to dictate nor to inform but to encourage discussion amongst the group, of which I am a member." That's enough from me. Where shall we go from here?

We looked at traditional gender roles, and that healthcare and education usually fall into the mother's domain. There appears to be a general tendency for fathers to be excluded by the system. This stems from a society where, traditionally, men are out at work, and women, even if they work as well, are responsible for childcare. Fathers, it was agreed, can miss out. Being 'left out' leads to a feeling of isolation and the loss of the bonding that is created by shared experiences, both good and bad. Communication: that seems to be the key, communication with schools, with hospitals and, most importantly, with partners! Communication is also important amongst ourselves. The most effective way to deal with worries and fears is to talk them through. They may still be there but at least they will be out in the open where they can be addressed. These issues can be painful to confront and to talk about. We all have our fears but it is important to realise that we are not alone. "I have felt isolated for a long time but I have never before been able to talk about it. I thought other people would not understand."

[redacted]

SOCIETY NEWS

Overview of 1998

by Chris Hodgson, Chairman

I would like to take a moment to reflect on the past year, which was something of a roller coaster ride for The Haemophilia Society. We have experienced some very significant highs and lows, but as we look forward to 1999 our direction is definitely upwards. The departure at the start of the year of Tony Wilson was unsettling for the organisation, but the appointment of Karin Pappenheim as Chief Executive in late March has provided much stability and movement in the right direction. I believe we now have a real leader, and with a very hard-working and committed team of staff, a great deal has been achieved this year.

There have been many developments and milestones this year in the field of haemophilia care: here's a brief summary.

January: Steve Fouch, the Society's first HIV Worker, took up his post

February: The Health Secretary announced recombinant for under 16s and newly diagnosed – a breakthrough for the Society's campaigning

March: Karin Pappenheim appointed Chief Executive.

April: Society ran first of a series of information evenings on Hepatitis C organised throughout the country

May: Presentation of our twinning with Russia at the World Federation of Haemophilia Congress

June: Membership survey questionnaire sent out from The Haemophilia Society to all members

July: Lobby to Parliament organised by the Society and Manor House Group, highlighting the plight of people with haemophilia infected with Hepatitis C

Health Secretary turned down appeal for financial assistance

August: Society's HIV worker completed review of NHS and voluntary sector services provided for people with haemophilia infected with HIV

September: *Every Day a Milestone* video for parents of newly diagnosed children with haemophilia completed

Lord Alf Morris, Dr Peter Jones and Professor Robert Winston accepted invitations to become Vice Presidents of the Society

October: A service was held and a Book of Remembrance opened at St Botolph without Bishopsgate Church, London, for all those who have died as a result of contaminated blood products. A commemorative Icon was also mounted in the church

The Department of Health agreed to fund the HCV Youth Project

November: The Belfast Haemophilia Day attracted record numbers

December: The Annual Draw winning ticket picked

Our thanks to Alan Tanner and in particular to Mary Ann, his daughter, for the creation of the Icon and the Book of Remembrance at St. Botolph without Bishopsgate; without their help it would not have been possible. This memorial reminds the Society to always be vigilant; the best treatment must always be available to those with bleeding disorders.

And finally, I would like to wish all our members, staff and trustees a Happy Christmas and a Peaceful New Year.

Haemophilia Society Awards

This year the award went to **Rosemary Spooner**, Research Assistant and Administrative Secretary to the UKHCDO, who has worked at the Oxford Haemophilia Centre since 1961. She has acted as Research assistant to Professor Robert Gwyn, Dr Biggs and Dr Rizza, and she is now Research Assistant to Dr Paul Giangrande. Rosemary has published 34 papers, is secretariat for the UKHCDO, collates records for the UK National Data and acted as Secretary to the Oxford Local group from 1970-1974. The award was presented to Rosemary at the UKHCDO AGM on 1 October 1998.

Local Group Award

This year's award winner was GRO-A Married to GRO-A and father of two sons, one of who has severe haemophili GRO-A was a committee member of the Southern Group of the Society for over 32 years, and served as the Group's Honorary Treasurer. GRO-A raised funds for the Society and Local group, offered support and encouragement to other members, and always ensured that if a member was ill or had died that the Society paid its respect and recognition through a gift or flowers.

Special mentions also went to: **Mrs Georgina Shiels** – Northern Ireland Group, who has looked after two caravans in Northern Ireland for many years and **Mrs Ishbel Cruickshank** – Grampian Group, who has run the Activity holiday at Craigower Lodge for 10 years.

New Local Groups Forum for next year

Next year we will be launching a new style of meeting for local groups to take the place of the previous Council meetings. With the introduction of the Society's new Constitution in 1996, Council meetings no longer have the role they used to under the old system. In future, they will be called Local Groups Forum meetings and will become more inter-active information exchanges for representatives from local groups to share news and good ideas, to hear about the Society's national activities, and to develop skills in fundraising, volunteer recruitment and other relevant areas. The first Local Groups Forum will be held in London on Saturday 24 April 1999 at the St Albans Centre, Leigh Place, Baldwins Gardens, London ECI.