Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392156

The Bulletin

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HEPATITIS C – A CAUSE FOR CONCERN? by Society Vice Chairman Simon Taylor

For many years, certainly since the use of factor concentrates became widespread in the 1970s, it has been well known that there were risks of the transmission of various different types of hepatitis. The most common of these, as far as haemophilia is concerned, was known for many years as "non A non B hepatitis", so called because no specific test was available. Over the last few years the virus has been identified and it is now known as hepatitis C virus or HCV, and a test has become available.

It is now clear, with the advent of this test, that virtually everyone who has been treated with clotting factor concentrates, prior to the introduction of processes such as heat treatment to destroy viruses in the mid 1980's, will have come into contact with the hepatitis C virus. Since 1986, all clotting factor concentrates should not have transmitted HCV and so only those treated after this date, such as small children, should not be at any risk.

In many cases, people will have been infected for many years, possibly up to 25 or more, without noticing it and without suffering any ill effects to date. In a minority of cases, **people are suffering from liver damage, and suffering a range of health problems** as a result.

The Haemophilia Society is following developments in hepatitis closely, liaising with our medical advisers and encouraging the provision of more information and research. On Saturday 12 March, the Society held the first of what may be a series of meetings devoted to hepatitis. Dr Christine Lee from the Royal Free Hospital, gave a talk and answered questions on the issue. In addition the Society has published a booklet on hepatitis which is freely available by contacting the Society's office.

The implications of hepatitis are not at this stage fully known, indeed one of the biggest problems we face is a lack of scientific and medical knowledge on the subject. A summary of some of the issues raised at the meeting follows, and may help to act as a check-list in seeking further information from your own centre.

- Everyone treated before 1985/6 will probably have been in contact with the hepatitis C virus;
- All clotting factor concentrates now in use in the UK are subject to rigorous anti-viral treatments and blood donations are screened for HCV, so it is most unlikely that any new cases should have taken place in the last 8/9 years;
- All patients' HCV status should be regularly monitored by their centre;
- The great majority of people who have been infected have had the virus for about 15 years and are well;
- Current thinking is that the majority of people will remain well, about 10% may progress to serious liver damage over 20 years;
- Treatment by the use of Interferon is a possibility, and is being further investigated;
- There is no vaccine yet available;
- Hepatitis C is very difficult to catch or transmit, and household contact is perfectly safe;
- Sexual transmission is very rare, but theoretically possible, and should be discussed with your centres;
- Alcohol use should be avoided, or at least reduced.

In most cases, HCV need not be a cause of immediate concern, but it is important that you discuss your own situation with your centre, and that this is kept under review over the years. The Society will pass on new information as it becomes available and the Society's booklet is available and will be updated as required.

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THE CHALLENGING WORLD OF HAEMOPHILIA

by Andy Cowe, Editor of The Bulletin

A glance through the contents of this Bulletin illustrates how lively and challenging the world of haemophilia is and how active the Haemophilia Society is.

The issue of hepatitis C presents us with many unanswered questions. There are many different views about the severity of the problem. The Society's intention is not to spread fear and alarm. We seek to ensure that the debate is properly informed. Our readers must be provided with the information that is essential to making decisions about our health and welfare.

The benefits and opportunities offered by the science of genetics are stimulating much interest. Knowledge in this area is of immediate relevance to those who may be carriers of haemophilia. The treatment possibilities offered by genetic engineering are exciting. We shall report on the latest news in the next Bulletin, following papers to be presented at the World Federation of Hemophilia Congress in Mexico.

We report on successes within the Haemophilia Society itself. Our Annual Report gives us reassuring news about our financial position. We have had great success with our Haemophilia Days – bringing the Society and experts in haemophilia to members in different parts of the country. Our survey of members' needs provides us with a clear indication of how we should develop our services. Our new staff are in post and building a sound foundation for progress.

The Haemophilia Society has a vital role to play in a world full of changes. It is a dynamic organisation with opportunities for all our readers and supporters to contribute to our future. Please help us to achieve our aim – improving the quality of life for people with haemophilia.

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DAVID WATTERS – The Chairman writes of years of devoted service from 1981 – 1993

The appointment of David Watters as a full-time Executive Officer of the Society marked a turning point in the organisation and administration of our work.

Up to then, we had the benefit of a conscientious, part-time secretary who coped valiantly in managing the office and the substantial correspondence which came in each day. Members of the Executive Committee and other volunteers gave much of their own spare time to maintaining contacts with members and giving advice and support to people with haemophilia and their families.

The arrival of David Watters led to a transformation in the office procedures and in our relationship with all concerned with the Society's affairs. For the first time, we had someone in the office throughout the whole of the day and the person concerned was not only able to devote all his time to Society affairs but he brought to it a high degree of professionalism and the experience of his previous work.

I first heard of David Watters in the 1970's when he was Director of Girls Alone in London Service (GALS), a charity formed to help girls arriving in London who were at risk amongst all the uncertainties of the Metropolis. He was introduced to me as the one who realised that boys as well as girls were in need of support and he was responsible for extending the organisation to care for them as well. "GALS" became "ALS" and David had made his mark!

His previous experience had been with a Lay Training Centre in the Church of Scotland, as a Social Worker at St Martin-in-the-Fields and with a housing advice organisation for single people and childless couples in London.

When David applied for the appointment with the Society he was the obvious candidate among those who were recommended. His references were outstanding and all who knew him thought he would tackle the appointment with enthusiasm, dedication and efficiency. They were not mistaken.

However, his introduction to the Society was treated cautiously. Some thought that the appointment of a professional administrator would interfere with the warm, personal relationship which the officers and Executive Committee had with members of the Society and particularly with the Groups which were spread throughout the country. The archives will show that sustained discussion turned on the title to be given to this professional person who was to come among us; the degree of apprehension may be discerned by the rejection of such titles as Administrator, Director or even General Secretary. We settled for "Co-ordinator" and such was his job specification when he arrived; he was to co-ordinate the activities of the volunteers but not to dictate, reorganise, administer or pressurise us !

Experience

The development of the Society from that day to this is a testimony to the skill, experience and competence of David Watters in building on the foundation set down in the formative years and to his patience and sensitivity in personal relationships by which he earned the confidence and support of those with whom he worked.

David applied himself immediately to establishing a firm financial basis and his success in this endeavour is seen in the improvement of the annual income from £25,000. to £600,000. within ten years. He showed particular gifts in strengthening the administration of our organisation, introducing us to strategic planning and a formal management and staffing structure which is subject to regular review.

There is no doubt that David's 'finest hour' and greatest achievement was in bringing to a conclusion the campaign for recompense for people with haemophilia affected by HIV infection through the use of blood products supplied by the National Health Service. In this campaign he worked tirelessly; he established close contacts with members of both Houses of Parliament and waited tenaciously on the Government officers concerned. He was pursued relentlessly by television interviewers and newspaper correspondents and, in the end, his efforts and those who worked with him were rewarded by the original grant from the Government which led to the formation of the Macfarlane Trust.

This record of David's achievements would not be complete without reference to his membership of the European Haemophilia Consortium and his commitment to the World Federation of Hemophilia. Nor should we overlook the fact that he continued to have considerable outside commitments in serving the community as a Justice of the Peace, Chairman of Social Security Appeal Tribunals and a Church Warden of his parish church.

Success

However, apart from this distinguished list of successes in administration, communications and campaigning, I pay tribute especially to his underlying concern for the people with haemophilia and their families whom we serve.

I know that David has formed an extraordinarily wide circle of friends in the Groups, the Centres and among the families who have looked to him for advice and I continue to admire the personal attention he has given to them. He was among the first to recognise the comfort which could be given to people in our Annual Service of Thanksgiving and Remembrance and I shall always be grateful to him for that.

Dedicated

All his friends will be delighted to know that he is now well settled in his new work in the Primary Immunodeficiency Association, an organisation which is in some respects similar to our own. It was providential that the appointment became available at the time he moved from the Society so, as they say, "our loss is their gain"!

Many people would like to contribute towards a presentation for David. I shall be pleased to receive contributions marked "David Watter's Presentation" addressed to me at the national office.

GRO-C

The Rev Preb
Alan Tanner

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GOING TO WORK

– by Dr Peter Jones, Director, Newcastle Haemophilia Centre

Some years ago I was privileged to read the diary of a man with severe haemophilia who had lived in the last century. Crippled with arthritis by early adult life he was forced to work manually to provide for his large family. When bleeds were particularly bad his sons took him to work lying on a hand-cart. In those days there was no treatment and no welfare state. You fended for yourself or went under.

It is salutary to think that this story probably still describes a usual way of life for most of the world's adults with haemophilia. Those who live in developed countries with access to treatment grow up with a distinct advantage. Contemporary therapy should ensure the loss of little (if any) schooling, and few careers are closed to those with haemophilia.

The Restrictions

Let's get the really unsuitable careers out of the way first. They are few, and the reasons for not considering someone with haemophilia for them are pretty obvious. These jobs include the armed forces and the emergency services. In addition, jobs which involve travelling or living in parts of the world remote from treatment facilities are usually out. I say 'usually' because I know people with haemophilia who have not disclosed their bleeding disorder when applying for such jobs. Most of those with a mild reduction of clotting factor get away with it. Those whose haemophilia is dependent on replacement therapy with factor VIII or IX do not. In trying to hide the diagnosis they may put both themselves and others at considerable risk. After all, is it really brave and can it be sensible to engage in a hazardous job which involves close teamwork in extreme conditions if you have severe haemophilia?

If a youngster sets his heart on joining the diplomatic service, or on becoming a fireman, the family should discuss the choices with his doctor. There are exceptions to every rule but in these cases it is always best to tell the truth about the diagnosis, and back it up with sensible opinion and medical fact.

The Importance of an Accurate Diagnosis

An accurate knowledge of the diagnosis and its severity can be crucial when deciding on a career. Someone with mild haemophilia or von Willebrand's syndrome can expect to compete on an equal footing with those without a bleeding disorder. Someone with severe haemophilia who has a high titre inhibitor or arthritis will usually (there's that word again!) find his horizons more restricted.

It may also be crucial to be able to describe what your diagnosis means when you go for interview or talk to workmates. As we said in a booklet about employment, published in 1980,* "Most employers and colleagues at work tend to be very helpful once they really understand what haemophilia is, and seeing how well you cope with it will probably win their admiration".

Also be prepared to deal with questions relating to AIDS. As a result of all the publicity members of the general public may think that haemophilia and AIDS are synonymous. If you don't feel like indulging their curiosity just say that it has nothing to do with you - your haemophilia is treated with safe products. Whether you are infected or not is of no significance to them, and you have the right not to disclose your HIV antibody status to anyone.

The Ideal Job

Given the chance the average young man would like to work on a sundrenched beach with unlimited access to girls, money and free time. Come to think of it, the average old man would too. But life is not (usually!) like that. So here is a description of the ideal job for someone with severe haemophilia:

He would enjoy work;

The employer would know of the haemophilia and have accurate and up-to-date information about the employee's disorder;

There would be an arrangement to provide cover during unavoidable absence;

Facilities for efficient and speedy treatment should be near at hand;

The job should not involve work likely to put heavy strain on joints and musculature, and should be in a warm, dry environment if the employee has chronic arthritis;

The job should allow movement and not confine the employee to long periods of sitting or standing in one position;

The rates of pay and conditions of service should be the same as those for non-affected employees.

Careers Guidance

All schools have teachers with experience in advising boys about their future careers. Two important points need to be made about the boy with haemophilia. First, parents should make sure that this advice is not coloured by misconceptions about the bleeding disorder. Second, advice should be sought early. If necessary either a letter or a visit from a member of staff at the haemophilia centre should be requested. The careers teacher then has up-todate information about haemophilia and an individual boy's prospects for his future.

Early advice should be broadly based, leaving as many options as possible open. These should be explored before narrowing down the field at the time of competitive exams. Take advantage of work experience schemes. Ask relatives and friends to introduce your son to their work. Encourage him but don't push him. Explaining the advantages of staying on at school or college in order to get as many qualifications as possible can be difficult. It is sometimes hard to appreciate how much easier it will be to land a decent job in the future if he has better qualifications than the opposition, if he sees his friends earning and living 'adult' lives outside the strictures of formal education.

Disability

In the United Kingdom anyone who is substantially handicapped when it comes to getting a job may apply to be included in a Register of Disabled Persons. In our experience such an application carries little benefit. After all, the employment of both disabled and able-bodied people is governed by the economic rules of supply and demand.

However, the government has just launched a new 'Access to Work' programme to help disabled people compete for jobs on an equal basis. A leaflet is available from local Jobcentres, or by 'phoning free on 0800 567 667.

Should an Employer Know?

The buck stops with the man with haemophilia. It is up to him whether or not he discloses his bleeding disorder, and that can be a very difficult decision to make. In general, my advice is to tell the truth. Be honest and explain how easy it is to control bleeds with self injection. Tell employers that they can expect a good work record. Emphasise that your haemophilia and its control will not be a threat to anyone else at work. Show how unspectacular and matter-of-fact haemophilia is when properly managed.

The question of disclosure is likely to arise for the first time when applying for a job, or for a place in college or university. Here my advice is not to disclose the diagnosis early in the selection procedure. Let people judge your application on its merits. You will have worked hard to prepare for selection. The decision to offer you a place should depend on how you compare with the other applicants in terms of the requirements for the post, and not on your haemophilia.

Wait until you have been offered the job before mentioning the diagnosis. Be prepared to fill in details for medical or personnel officers, to answer questions and to back up your information by calling on the expertise available to you at your haemophilia centre. Remember that employers have a duty in law not to endanger the health and safety of their employees, and that includes you. Most will respond very positively to knowledge of your haemophilia and of any measures you need at work to help you manage it and get on with the job. They will understand the need for you to have occasional check-ups at the centre, and allow time off for this. In my experience it is very rare for an employer to want a note saying that someone has had to attend for follow-up, but if that is needed it is there for the asking. Obviously, employers like good warning of appointments so that work rotas are not disrupted.

Treatment at Work

I do not know many men with haemophilia who regularly treat themselves at work. Most prefer to be on prophylaxis, or to wait until they get home before giving themselves an injection. If a bleed starts early in the day this delay can be dangerous. It may lead to unnecessary disruption in joints or muscles with more chance of long-term problems, or it may result in the need for time off work in order to rehabilitate a joint. It would have been far better if arrangements had been made in advance for a quick injection of clotting factor.

TREATMENT TIPS

Do not try to hide your need for treatment. There is nothing whatsoever to be ashamed of in controlling your haemophilia. Indeed, the fact you are able to manage your life so easily should be a source of pride to you. Part of that pride should stem from your professional approach to good technique. That includes cleaning up after your injection and disposing of all used equipment, especially needles, safely. The best way of doing this is to keep a sharps disposal box at work and to take it home with you for disposal at the centre.

If the firm is a large one there will be facilities for treatment on site. After all, there are many conditions that require intermittent treatment that are far commoner than haemophilia. The obvious one is diabetes, and everyone knows how necessary it is to control that properly, usually with injections of insulin.

In the case of smaller firms remember that the things you need for safe treatment really are minimal. A clean environment and 10 minutes peace should allow you to inject with no disruption to other employees. Either carry your concentrate and kit to work with you, or store a supply in your locker or a fridge; don't let concentrate go out of date if you rarely need to give it.

Know Your Limitations

Challenge is something that some people relish and others prefer to disregard. Those with haemophilia are no exception, but my experience is that young people with haemophilia are more likely to respond to a challenge actively than their friends without haemophilia. That's great, and just how it should be!

But continual challenge at work can be very wearing, especially if bleeds or their aftermath leave you below par and not really up to the job. By all means prove yourself, but do remember that both body and mind need frequent rest as well as activity if they are to continue to perform well.

The highest quality of work is done by people who are motivated and able to perform at a good level consistently. That means keeping fit with a good diet, plenty of sleep and regular exercise. Fat sleepy people with haemophilia are just as likely to underperform and dislike their jobs as fat sleepy people without haemophilia!

Main Lesson of the Day:

Go for the best job available! Don't let haemophilia stand in your way!

(*updated in the new edition of Living With Haemophilia, to be published later this year)

SOCIETY OPPOSES PATENTING OF GENES

The Society has backed the views of the Genetic Interest Group that human genes should not be patentable.

The Genetic Interest Group (GIG) is a national umbrella body for voluntary organisations, charities and support groups for all people affected by genetic disorders.

In a briefing paper, recently handed to the Society, GIG expresses concerns over the growing number of human genes being patented.

GIG believes that technical processes allowing the understanding of the structure and functioning of a gene should be patentable, but does not believe that the patenting of human genes should be allowed both on legal and moral grounds.

Currently the EC Directive on the Legal Protection of Biotechnological Inventions is being revised to take into account recent developments.

GIG is concerned about the attitude taken by the Department of Trade and Industry (DTI) to the revision of the Directive. The DTI's position is that human genes isolated outside the human body and of known function should be patentable. This directly contradicts the view of GIG.

The Society has decided to back the GIG view and will be lending its support at national and European level.

Graham Barker commented: "At the Society we support the search for a gene therapy treatment for haemophilia and believe that allowing particular human genes to be patented will have a negative effect on this research. We have decided to oppose the patenting of human genes because we believe it is not in the interest of people with haemophilia."

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SOCIETY VICE CHAIRMAN CHRIS HODGSON

As a part of our continuing series of profiles of members of the Executive Committee the Bulletin spoke to Chris Hodgson.

Chris is 53 years old and

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His career background is in the motor trade. He was in the motor business from 1958 until 1993, becoming the Chairman of a group of three garages and Managing Director of the group's Volvo dealership.

He decided to reduce his workload last year, and now runs a small contract hire and consultancy business from home.

GRO-A

Society for several years and describes the Group as primarily operating a self-help service offering support to anyone they hear about as well as their regular attenders.

As a result of his interest in helping people with haemophilia and HIV he is currently taking a two-year counselling course.

A Society representative on the Macfarlane Trust for the last two years, Chris aims to promote an understanding of the problems faced by people with haemophilia. As a part of this role he will be involved in trying to set up a needs assessment of everyone registered with the Trust.

Chris was elected onto the Executive Committee after the sad death of Ken Milne at the end of last year. At the Society's AGM this March he was elected to the post of Vice Chairman.

He is no stranger to the work of the Executive Committee. His wife, Jane served on the

Chris Hodgson.

Executive for three years, retiring in the middle of last year.

When asked about the prime areas that he would want to address as Vice Chairman, he said that he would want the Society to look after the needs of all people with haemophilia and their families.

"In particular we must strive to maintain and improve standards of care," he said. "We must make sure we have access to the full range of available blood products and keep up to date with HIV and hepatitis developments."

Chris will be serving on the Services Committee under the chairmanship of Simon Taylor, and one of the plans is for each member of the Committee to visit two local Groups per year so that they can listen and act on any problems that a Group may be experiencing .

"I am particularly keen that the Society remain strong and vigilant in the face of Health Service cutbacks and faces the challenges of the future with energy and unity."

Married with two sons, Chris lives in Hampshire. Like his sons he has a keen interest in sport. "They are both fanatical footballers and play for their schools," he said. Chris is also an avid angler and up till two years ago was a gliding instructor.

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WHAT DO MEMBERS WANT FROM THE HAEMOPHILIA SOCIETY

– by Graham Barker, Director of services and development.

Last year the Society undertook a survey amongst the membership to try and find out what you felt about the services we currently offer and what you would like in the way of new services.

As part of the Strategic Plan it was agreed that it was essential that the needs assessment exercise be carried out to find if there were groups within the membership that had specific needs that the Society should try to meet.

The results of the survey were reported to the Services and Executive Committees. The report analysed the views expressed by the membership and made a number of recommendations for action including proposals for new services, some of which are highlighted in this report.

The clear message coming from the survey was that people wanted information and that they wanted contact and support. The information was wanted both in written form and by telephone, where quick advice and reassurance was the priority.

Contact

Providing contact with others was seen as one of the Society's major roles. This was emphasised both by those who were getting support from their local Group and those who were getting no support and felt isolated. Ideally, people want contact with those living locally but where this was not possible, 'phone contact was wanted.

On the whole, most respondents were happy with the services provided by the Society. The Bulletin was described as informative, interesting and essential reading. However, although the articles on treatment and scientific developments were wanted, there was a clear demand that these should be in a simpler language. There was also a request for more articles written by people with haemophilia conveying their own personal experiences. Update was not as well received, with many people questioning its purpose. The Executive has since decided to drop Update and produce four issues of the Bulletin each year.

The Society's other publications provoked little feedback, either positive or negative. It may be that members are not fully aware of the Society's publications and that more should be done to advertise and promote them.

In the eyes of parents there is no doubt that the Armourpage service is the most popular service provided by the Society

Most respondents who *requested information* or advice from the Society by telephone were happy with the service. This was especially true for advice on specific topics such as travel or insurance. One or two respondents said that they did not ring because they thought the Society was too busy and they should not waste our time.

The benefits advice and advocacy service was well thought of, though many people seemed unaware of the benefits they could claim or how the Society could help.

Haemophilia Days were well liked by those who had attended them as much for the sharing of experiences and opportunity to talk and make contacts as for the information given. Those who had not attended cited cost and distance to travel as the major obstacles, having children or a disability was also mentioned.

Members were also given the opportunity to comment on new services, and some of *these were followed up* by a telephone interview.

There was considerable support for the idea of an introductory pack for the parents of newly diagnosed children. Although Peter Jones' book – Introduction to *Haemophilia* – was well liked, many felt that less information in a more easily understood form was required, possibly written from a parents' perspective. If this information could be produced in a standard format it could form part of a loose leaf folder to be added to at later dates.

Considerable interest was shown in the Society producing a series of simple fact sheets covering a range of different subjects. These could all be produced to a standard format for ease of storage. Articles from the Bulletin and other journals could be reproduced in the same format and distributed on request.

Parents were very positive about the idea of informal local parent support groups. They wanted the opportunity to simply talk with other parents, often over a cup of coffee while the children played.

Being able to meet with other parents to discuss common problems and concerns without having to travel any great distance appeared to be the greatest need that parents had that they felt the Society could meet.

"People wanted information and they wanted contact and support. The information was wanted both in written form and by telephone"

There was also considerable interest in the Society providing more information and support via the telephone. One suggestion was that the Society should have a dedicated member services line that would be available during certain advertised hours. Another suggestion was that the Society should operate a helpline staffed by volunteers, such as experienced parents who had themselves had direct experience of living with haemophilia.

Support

Another form of support that people wanted and felt the Society could provide was a register of contacts. Under this system someone could ring up and ask to be put in contact with someone in a similar situation, for example the parents of a young boy with inhibitors. At present the Society's database cannot cope with this kind of request. Although it is true that a number of Groups provide this kind of support, not all Groups are able to do so and a large number of members have no contact with any Group. On the basis of the survey's conclusions, the needs assessment *report went on to make* a number of recommendations about the services that the Society should consider providing. A number of these are already being acted upon. It has been accepted that increased support for parents is a priority area. A start has been made in circulating a questionnaire to local Groups. In this way we can find out what support is currently being provided; examples of good practice; and what the national office can do to support parents not in contact with a local Group. A questionnaire will also be sent to centres to find out what support they provide for parents.

Ideas

From these two questionnaires we hope to get material and ideas for an introductory pack for parents of newly diagnosed children; examples of good practice by local Groups that can be publicised; practical ideas on how we can support informal local parent groups; and a database of existing support to parents. At the same time we are taking on a volunteer to set up a contact database of parents. The volunteer will contact the members to see if they wish to take part. If they do, they will be asked to give some basic information that will be entered into our database. Eventually this will enable us to respond to those requests from parents who want to be put in touch with another parent wherever they happen to live.

"We are looking at ways of providing information and support to people affected by hepatitis C"

We have taken on a member services officer, Kate Richards, whose primary responsibility is to support members in claiming benefits, in particular the Disability Living Allowance. She is also responsible for providing information and advice on a whole range of issues affecting people with haemophilia, including housing, insurance and travel. In time we hope to produce a range of fact sheets on these and other issues to do with living with haemophilia.

Information

We are looking at ways of providing information and support to people affected by hepatitis C. A booklet has been produced and a number of hepatitis meetings are being planned. As the scale and nature of the problem becomes more apparent we will try to respond to members' *expressed needs.*

Support is being given to the Birchgrove Group to develop its support for people affected by haemophilia and HIV throughout the country. Discussions are also underway with other HIV agencies to try and open up access to their HIV services.

At the same time we will continue to organise events like the Haemophilia Days that bring all parts of the haemophilia community together to discuss common problems and develop joint solutions.

We will try to ensure that the services that we offer are those that the members want. We need your comments and feedback on all the services that we provide. The success of the Haemophilia Days is largely due to lessons learned from the evaluation sheets that people fill in on the day.

The first hepatitis day has been evaluated and we hope to make improvements to the next ones based on the comments of those who attended.

"We will try to ensure that the services we offer are those that the members want"

With your help and suggestions we will be able to make sure that the improvements you want are made. Obviously resources are limited and we will not be able to respond to all your suggestions, but we will do our best to provide services that meet your *needs.*

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NEWS FROM THE BIRCHGROVE GROUP

The Birchgrove Group has recently held a national meeting in Cardiff of its regional group representatives where the current position regarding services on offer to those with haemophilia and HIV was discussed in detail. The Group is planning to hold its Annual General Meeting during the latter half of the year (funds permitting) and it will be publicising this nearer the time.

Several new groups of HIV positive people with haemophilia have expressed interest in meeting together, and the Birchgrove Group are offering their support and assistance to anyone who is in a similar situation.

It is believed that the Macfarlane Trust is considering undertaking a needs assessment to investigate the current situations of those with haemophilia and HIV. The Birchgrove Group is keen that this research should be undertaken as quickly as possible and would hope to help the Trust in this endeavour.

Recently, some members have become interested in the beneficial effects of vitamins and minerals in fighting some of the side effects of HIV. A detailed information sheet has been prepared which discusses the supplements concerned and suggests where they may be obtained. If you would like a copy please send a stamped addressed envelope c/o The Birchgrove Group, P.O. Box 313, Canterbury, Kent CT1 1GL.

PUBLICATIONS

The Society has a number of publications available for our members. We are constantly updating the information that we provide, so at any time one or more of the booklets will be out of circulation for revision. If you would like to receive any of the publications listed below please telephone the Society national office to check availability.

The Essentials of Haemophilia Care

Joint Care and Exercises

Teaching Children with Bleeding Disorders

Hepatitis

Children's Haemophilia Book

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