# THE HAEMOPHILIA SOCIETY

*.....working for people with haemophilia and related bleeding disorders*

## *Haemophilia and hepatitis C*

**WHAT IS HAEMOPHILIA?**

**HISTORY OF HEPATITIS C INFECTION IN THE HAEMOPHILIA COMMUNITY**

**HOW ARE PEOPLE WITH HAEMOPHILIA AFFECTED BY HAVING HEPATITIS C?**

**WORK OF THE HAEMOPHILIA SOCIETY**

*Karin Pappenheim, Chief Executive or Lucy McGrath, Hepatitis Worker*
*The Haemophilia Society*
*Chesterfield House*
*385 Euston Road*
*London*
*NW1 3AU*
*Tel: 0171 380 0600*
*Fax: 0171 387 8220*
*e-mail: karin@haemophilia.org.uk*
*lucy@haemophilia.org.uk*
*website: www.haemophilia.org.uk*

## WHAT IS HAEMOPHILIA ?

***........haemophilia is a bleeding disorder***

Haemophilia is an inherited bleeding disorder caused by the absence of certain clotting factors in the blood.

It is a common misconception that people with haemophilia bleed all over the place if they cut themselves. They do not bleed more profusely or faster than normal - just longer. The biggest problem is not from bleeding cuts or scratches, but from spontaneous internal bleeds into the muscles and joints - these cause damage to elbows, ankles and knees.

There is at present no cure for haemophilia but it can be treated and the condition managed. Treatment takes the form of replacement of the missing clotting factor. There are several related bleeding disorders caused by the absence of *different* clotting factors. Although haemophilia only directly affects men, some of the other bleeding disorders can affect men or women.

## HISTORY OF HEPATITIS C INFECTION IN THE HAEMOPHILIA COMMUNITY

***.....nearly all people with haemophilia over the age of 13 contracted hepatitis C through their treatment....over 4000 people infected, 1200 of whom were co-infected with HIV***

In the 1960s an important step forward was made in the treatment of haemophilia, in the form of the availability of clotting factor concentrates, manufactured from blood. Many donations of blood are pooled together and the component parts separated out by a process called fractionation to produce pure clotting factors. These blood clotting factors have in many ways greatly helped people with haemophilia, particularly severe haemophilia, by limiting joint damage caused by bleeds.

In the early 1980s it became apparent that HIV was in the blood supply and that people with haemophilia were being infected. However it was not until 1985/6 that viral inactivation procedures were introduced into the manufacture of clotting factor concentrates, in particular heat treatment.

This was too late for many people with haemophilia, with over 1200 people infected with HIV, of whom over half have died.

Some haemophiliacs who received blood clotting factors before 1985 also developed an unknown form of hepatitis - called 'non A non B'. In 1989 this virus was identified and is of course the hepatitis C virus. When tests for the virus became available it became clear that **over 95% of haemophiliacs who received treatment for their haemophilia before 1986 were infected with hepatitis C.** This includes not just people with severe haemophilia who require regular treatments, but also those with mild or moderate haemophilia who may have only been treated once or twice in their life. It includes both men and women with von Willebrand disease, and some carriers. More than 4000 people were infected this way.

# HOW ARE PEOPLE WITH HAEMOPHILIA AFFECTED BY HAVING HCV?

***.....families affected through several generations....a huge tragedy affecting all those with haemophilia whether mild or moderate...men, women and children infected....no financial support available***

This virus has had a huge impact on the haemophilia community, following on from the devastating effect of HIV. Nearly everyone over the age of 13 is infected; many with mild or moderate haemophilia which would not normally cause them many problems during their life, have been infected, including many women with the bleeding disorder von Willebrand Disease and some haemophilia carriers. In some families many generations are infected: brothers, sisters, uncles, nephews, grandfathers. Individuals are affected differently; for some the virus has had a very damaging effect on their lives, whereas for others it has had only a limited impact. The impact is not just in terms of physical health but also has social, financial and psychological implications.

A major problem facing all those infected is that it is not yet possible to predict which individuals are likely to develop cirrhosis, liver cancer or other more serious non-hepatic complications. While some will remain well, they all have to live with uncertainty over their future health and the stress and anxiety this creates. This is a particular worry for parents of infected children.

Regardless of their current health, all those who are hepatitis C antibody positive face prohibitive premiums for life insurance and, for the many whose health is affected by HCV, the biggest problem is reduced income from having to reduce their hours of work, give up opportunities for promotion, take a less demanding job and in many cases give up employment completely. Many have become increasingly dependent on state welfare benefits and as well as losing income, many also face increased costs through expenditure on medicines, alternative therapies, dietary requirements and travel expenses.

Family relationships are put under tremendous pressure with the infected person unable to participate fully in regular daily activities such as working, household tasks and playing with the children. Many people report severe mood swings, inability to concentrate, depression and loss of libido. The risk of transmission, either through sexual or household contact, is very low, but can give rise to anxiety and all these factors have put intense strain on many family relationships.

Where children are infected the problems are often particularly acute. The education and schooling of many teenagers has been affected by HCV, for example by missing time through interferon treatment and many infected children have experienced deep psychological problems and a loss of hope.

Anger at what has happened is a feature for a lot of people with haemophilia. Within the Society there is an organisation called the Birchgrove Group which has very successfully identified and publicised the services needed by people with haemophilia and HIV infection. A group of Haemophilia Society members known as the Manor House Group has also formed and has collected and disseminated a great deal of information about HCV infection and campaigned for the Society to develop its response to HCV more fully and to represent those affected. This group has also campaigned vigorously with the Society in order to try to get recompense for those infected through blood clotting factors, along the same lines as the recompense offered to those with HIV and haemophilia in the form of the Macfarlane Trust.

## WORK OF THE HAEMOPHILIA SOCIETY

*....support, advice, information, campaigning......*

### Areas of work

The Haemophilia Society has a hepatitis worker, and provides support, advice, information and advocacy for people with haemophilia and hepatitis C. This is provided through:

- **Fact sheets** on different aspects of hepatitis C, ranging from treatments and liver biopsies, to how to manage fatigue and aspects of nutrition. These fact sheets are written by experts and are usually fairly detailed
- **Conferences** around the country for people with haemophilia and hepatitis C and their friends/families
- A **three-monthly newsletter, "C Issues"** which includes information about latest medical developments, personal accounts, the campaign, and Society events
- **Telephone advice** on most aspects of hepatitis C, including treatments and benefits
- **Advocacy** on an individual basis to ensure people get the best treatment
- A **telephone support network** which puts affected individuals in contact with others in a similar situation
- **Hepatitis support and information evenings** -evening meetings round the country with a presentation by a nursing or medical speaker followed by the opportunity to chat informally with other people in a similar situation, and to share experiences of living with the virus
- **Campaigning for improved treatment** for this group, through input into policy at national and local levels, discussion with haemophilia centre directors
- **Campaigning for financial assistance for people in this situation** -this campaign has been ongoing for 4 years and involves parliamentary and media activity.

### New projects

A major area of work which will be undertaken in 1999 is a project for which we have just received funding to provide support and information for young people - aged 12 to 21 - with hepatitis C and haemophilia, and their parents and carers.

In addition to the areas of work mentioned above, we hope to increase the range of our fact sheets on hepatitis C, and also to update some of our existing literature.

We may, subject to demand, be holding a conference about hepatitis C for haemophilia professionals to discuss medical and social issues affecting people with haemophilia and hepatitis C.

On a positive note meetings have recently taken place between the Society, The British Liver Trust and Mainliners looking at ways we can work together to see that appropriate services are developed for people with hepatitis C and are made available to all, regardless of how the disease was acquired.