



**THE
HAEMOPHILIA
SOCIETY**

Update

Number 3 September 1993

DLA MOBILITY AND CARE COMPONENTS

Since the DLA scheme was introduced in 1992 the Society has been directly involved with almost 100 applications. A striking feature of the cases dealt with by the staff at the national office is that a letter from the

Society helps to secure payment of the benefit! Of the 46 cases which have been fully resolved - i.e. the benefit granted - 40 were granted immediately the Society became involved.

The short message is: if

you have applied and failed, contact the General Secretary and he will advise you on how to take your application forward. It is ideal if you can send him copies of all the correspondence you will have received from DLA.

We advise everyone aged five years and over who has less than 5% clotting factor to apply for Mobility Component: those over, say, twelve years should have evidence that actual or potential joint damage was a result of bleeding into lower limb weight bearing joints.

The care component should be available to all children from an early age, certainly prior to their first birthday, provided they have less than 5% clotting factor. It is important to show that the baby with haemophilia requires more attention than his non-haemophilic counterpart: we understand this, but conveying it to an adjudication officer can take a little longer! Once granted,

payment of the care component should then continue uninterrupted until at least the age of twelve years. There may be difficulties in obtaining the payment beyond the age of twelve. In later years damaged joints may mean you need help with dressing, washing, toileting, feeding, treatment of haemophilia and so on - problems which a number of elderly people have but which are exacerbated by haemophilia.

PLEASE ASK FOR OUR HELP WITH YOUR APPLICATION: we can arrange for an application pack to be sent to you, let you have our notes on completing the application forms, review your application before you send it in and make copies for your records and our records just in case a review is needed. It is our pleasure to help everyone with haemophilia to secure the benefits to which they may be entitled.

COMMITTEE CHANGES

A few years ago, after the CERT report, the Executive Committee shared its work among three committees which looked after different aspects of our work. The Resources Committee looked after matters, personnel, etc; The Member Services Committee looked after the provision of services - e.g. grants, state benefits, etc. to people with haemophilia. The Policy and Development Committee looked after our policy on all matters affecting people with haemophilia; campaigns, and the development of new services through, for instance, the Strategic Planning process.

At an Executive Committee Day Conference during May it was resolved to change this structure and to have only TWO committees to look after the various aspects of the Executive Committee's work.

They are currently affectionately known as Committee 'A' and Committee 'B'.

Committee A is our 'internal' Committee which does everything necessary for us to function as a Society e.g. look after fund-raising, administration, the constitutional and legal matters affecting us as a charity and a company limited by guarantee.

Committee B, on the other hand, gets on with the real business of providing the services to people with haemophilia who we are in the business of serving - i.e. they look after things external which benefit you.

For the moment a convenient way of remembering which person deals with a subject is that Susan ARCHER looks after Committee A and Graham BARKER deals with Committee B.

HEPATITIS C VIRUS (HCV)

We continue to receive enquiries from members who are concerned about hepatitis in all forms but especially HCV. We have just finalised our booklet on hepatitis and it will be ready for sending to members who have enquiries in the near future. PLEASE let us know if you want to receive it since we will not be sending it to all our mem-

bers. A quick phone call is all that is necessary!

We would also remind members that lawyers are looking into legal aspects of potential for compensation claims. If you are interested in such a course of action please contact the General Secretary who will be able to give you details of lawyers with experience in the field.

WFH CONGRESS - MEXICO CITY APRIL 18-22 1994

Plans are well advanced for a travel package to enable UK delegates to travel to this important Congress where people with haemophilia from all over the world will be able to meet to learn of new developments in treatment and care and to share experiences alongside all those who care for them. At the time of writing specific details are not to hand but will be available in the near future. It looks as if we will have a package which will give flights from London to Mexico City on Saturday 16 April,

staying in a hotel on a room only basis, returning the following Saturday to the UK. The costs are estimated to be from £850 subject to the hotel selected. Full details will be mailed to all Centres and members requiring details should simply write and ask for them to be forwarded. It will be important to note that all payments will have to be made well in advance and that deposits will be required. Our arrangements are being made through Champion Travel.

CARING FOR PEOPLE WITH HAEMOPHILIA

THE HAEMOPHILIA SOCIETY

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THANKSGIVING AND CAROL SERVICES

Our Annual Service of Thanksgiving for people with haemophilia who have died from HIV related illnesses will once again be held in London at the Church of St Botolph Without Bishopsgate on Saturday 30 October at 3pm. This service is open to everyone who wishes to be with us as we remember, with thanksgiving, those who we have known and loved, worked beside, been cared for and loved by, shared time and experiences with, those we have cared for as friends, family members, doctors, nurses, social workers, physiotherapists, and so on. It is an occasion for everyone and no one should feel that they cannot attend.

As has become our practice, there will be a very special act of remembrance when we place our own written thoughts about those we remember on the altar. If you cannot attend, please send any thoughts or messages to us marked very simply: "PRIVATE AND CONFIDENTIAL FOR 30 OCTOBER". They will be passed to the Chairman and he will make sure that all such messages are destroyed afterwards. Please do not enclose anything else in your envelope as we will not open it or read the contents.

Our Annual Carol Service will be held on Friday 17 December at 6.30 pm, again at St Botolph Without

Bishopsgate. Please come and bring your friends to this very special event which is growing in popularity each year.

IMPORTANT NOTE
- In the last edition of The Bulletin we incorrectly reported that the Service of Thanksgiving was on October 20. The correct date for the service is Saturday October 30 at 3pm. The Society apologises for any inconvenience this error may have caused.

MONOCLONAL TREATMENT FOR HIV+'s

It has long been the Society's public view that patients with haemophilia who are HIV antibody positive should only be treated with high purity products. However, there is now increasing evidence that benefits to those who are HIV antibody positive only come from monoclonal blood products.

We are distressed to hear rumours that in some Centres patients are being taken off

monoclonal product. Please let us know if this is affecting you since we would want to discuss the situation with those responsible for purchasing your health care.

Equally, if you are positive and have asked for monoclonal product and been refused it, we would like to hear from you so that we can discuss that matter with the relevant authorities. This applies particularly to those

living in Scotland and Northern Ireland.

It may be that we are seeing the frightening first fruits of a cash-led health care system for people with haemophilia - those who are keen gardeners will know that it is often best to 'nip first fruit in the bud' so that the crop is better later on. This makes it very important that we know what is happening to you in terms of your haemophilia care.

EXECUTIVE COMMITTEE WEEKEND

Each year the Executive Committee spend a weekend considering various aspects of the Society's work. This year they will be meeting in London over the weekend beginning on Friday 29 October and continuing through to Sunday 31 October. Among the items they will be discussing will be a recent review of staff and premises which has been carried out by Professor Leo Evans, a member of the Committee, as well as subjects relating to HIV and hepatitis and the whole future direction of the Society.

STRATEGIC PLAN

Graham Barker continues to work on the responses to the Strategic Plan. Thanks to all those who have completed and returned the questionnaires - this has been very helpful. Please do let us have views on the services you would like us to consider providing for people with haemophilia - a letter to Graham will make sure that your views are considered.

A very specific area on which we would welcome ideas for consideration relates to HIV and AIDS in people with haemophilia. Our services are currently being rethought and any input would be warmly welcomed. This too is part of Graham's remit and he would welcome any views as part of our ongoing review of services to people with haemophilia.

PARTNERS IN SE1

During the summer months we have been fortunate to have the services of Matthew Ellis who has worked at the Fund-raising Desk. Matthew is a student who served with the Society as part of his work experience during 1993. One of the ideas which Matthew has taken forward is 'Partners in SE1' - an idea which the General Secretary had many moons ago but had never been able to give time to. Well, Matthew took hold of the idea and has worked hard on it and the results should materialise in the very near future.

The idea was not so much to raise money from national companies based, like the Society, in London SE1, but to bring together expertise for the benefit of people with haemophilia. That is possibly best illustrated by the fact that the Central Office of Information (COI) - a near neighbour - has undertaken to design all the brochures and the presentation boards for the launch of Partners in SE1. Sea Containers - again, near neighbours on the riverside, will host the event. We have already received support from a number of SE1 companies and we hope in this way to extend our relationship with local national businesses to our mutual benefit.

DEC

DEC stands for DIGITAL EQUIPMENT CORPORATION who have recently donated an eight station network computer system to the Society. Indeed this very edition of Update is the first document to be drafted on it! We are extremely grateful to Digital for this wonderful gift which, we have no doubt, represents the largest single donation ever received by the Society. It is all 'state of the art' equipment and we are all very excited about the uses to which we will be able to put it in the near future!

We will be expressing our appreciation to Digital in the next Bulletin in a more formal way but meantime wanted to let you know how generous they had been to your Society.

HAEMOPHILIA DAYS

As mentioned in The Bulletin, we have a programme of Haemophilia Days for autumn and spring. They are as follows:

October 2 Exeter
October 23 Birmingham
November 27 Stockport

In addition we will have a further Day on February 19 in central Scotland - precise details to follow but do note it in your diary and let us know of your interest so that we can begin to plan this 'first' for Scotland!

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