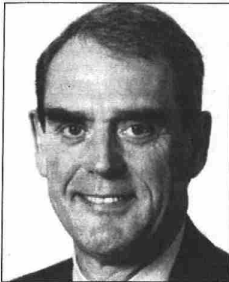


MFT Newsletter

FROM THE CHAIRMAN



Peter Stevens

Although the General Election has not changed the governing party, it has brought at least a couple of changes of significance to the Trust. Firstly, there is a change of Minister at the Department of Health with responsibility for us – in place of Lord Hunt we will now be among the issues handled by Yvette Cooper. I am looking forward to meeting her when she

returns from maternity leave and to briefing her on the needs of the Trust and of its registrants.

Recent discussions with the civil servant at the Department, with whom we are in frequent dialogue, have shown that there is an understanding that the Trust will be operating and will need funding for many years yet. Far from the short life originally expected when the Trust was set up in 1988, the Department, like the current Trustees, recognises that we will have responsibilities reaching far ahead, not just for our current registrants but for their dependants, including children who might not yet even have been born. I find it reassuring to know that the Government is thinking along these lines.

Another development that has emerged since the Election appeared in a recent speech by the Secretary of State for Health, Alan Milburn, in which he forecast the introduction of "no fault compensation" for errors arising in the National Health Service. Although the Trust can take no part in campaigning, the Trustees are, of course, well aware of the efforts of some of our registrants and of the Haemophilia Society to have the effects of infection with the hepatitis C virus given similar recognition to those of HIV infection. Mr Milburn's speech will be of great interest to us all.

The Department has recently undertaken a comprehensive management audit of the Trust, looking at our financial controls and our treasury, performance and grant management. The resulting report has made a great many recommendations on both strategy and operational aspects, many of which, I am glad to say, we had already been able to anticipate as a result of recent appointments to the Board of Trustees. The report, and the actions that are now being taken, reflect the

transition of the Trust from what had originally been designed for a life of not many years to an operation that must function soundly and efficiently, funded by tax revenues, for several decades to come. All those who are or might be beneficiaries of the Trust should be encouraged to know that its longer-term future is being considered so constructively.

The Trustees continue to press the Department to raise the rate of funding so that we can continue and develop the assistance we give to our registrants and their families. In an age of ever-increasing financial stringency in all areas, our perception of what we need to do is bound to be subject to intense scrutiny and to be required to compete for scarce resources with other deserving causes. We will continue to press on your behalf.

Consideration is being given to the development of a website for the Trust, as a means of adding to the communication between the Trust and its beneficiaries. The proposed format is included in this Newsletter. We will not proceed until we know that what we are doing is well supported. Anybody who would like to comment on the proposal is welcome to get in touch with staff in the office. The more views we can take into account at the planning stage, the better.

You will be aware of the departure of Jenny Jackson, who has been the Trust's Benefits Adviser for many years. She has been a source of great help and immensely useful advice to many people over that time, and we shall all miss her. I wish her well in her future career.

Since the last Newsletter I have made some further visits to Centres and met more of our registrants. There are still many more Centres from which I have not heard. I remain willing to travel anywhere to meet people who would like to talk to me about the workings, policies, future or any other aspect of the Trust. Please do not hesitate to ask your Centre to set up a meeting or to contact the office or me direct if you would like me to come and visit. The best way that the Trustees can know how to be of help in the future is to meet and listen to those we are appointed to help; nobody should hesitate from asking for the opportunity to talk to us in order for that objective to be met.

Peter Stevens

CENSUS UPDATE

At the beginning of the year, we sent a census form and letter to all those registered with the Trust and their dependants. So far 355 forms have been returned and staff are working hard to update data on electronic systems and check that your payments are correct. We have found a number of people who were not receiving sufficient Regular Payments from the Trust, almost certainly because we lacked information to calculate rates properly. Occasionally we have also found that we have been paying too much. In such cases the Trust will always give at least 3 months warning before reducing payments to the correct level. We have also been checking payments to widows and dependent children, amending as necessary. All this work is very time consuming, and as those of you that have visited our offices will know, we are a very small team. However, we hope to be ready for the Census deadline of 24th October 2001.

If you have not returned your Census form, either because you have lost it, or it has proved too daunting to complete, please let us know. We can send you a new form if the first one has been lost, or we can send a form to your Centre and ask staff to help you to complete it. If you have decided not to complete the form, we must assume that all information currently held about you is correct, and must assume your agreement to the Trust holding such information.

BENEFITS ADVISER

As many of you will know, Jenny Jackson, the Trust's Benefits Adviser for more than 5 years, left the Trust at the end of May. At that time we were confident that the vacancy would shortly be filled. However, as luck would have it, the first person to accept our offer of employment developed serious domestic problems that only came to light on the day she was to have taken up post.

After further searches, we have now offered the post of Benefits Adviser to Caroline Clisby, who has many years of benefits advice work behind her, both for local CAB's and for specialist disability organisations. Carol (as she prefers to be called) will not be able to start work with the Trust until some time in September because she must give adequate notice to her present employers. Meanwhile Claudette, Susan Daniels and I are all doing our best to respond to benefits queries as they arise. Sometimes the most practical option is for registrants to go to their local Citizens Advice Bureau, as advice offered there will always be accurate and up-to-date. However, if you have benefits problems that need urgent help, do please call us. We will always try to track down the right advice for you, even though we may not be qualified to represent you at tribunal!

WEEKEND MEETING FOR BEREAVED FAMILIES

As part of the Trust's Bereavement Project, a residential meeting will be held in Sheffield over the weekend of 22/23 September 2001. The meeting is planned as an informal 'get together' in a comfortable hotel with facilitators available for those people who might like to talk with others in a similar situation about their feelings and experiences. So far applicants include parents, partners, children and siblings. We hope that as a result of the weekend, more local support networks can be set up where people need them. Trustees have approved funding to meet the cost of the weekend and the establishment of further support groups. We are doing our best to contact all

families of those registrants who have died, but inevitably many people will have moved house and moved on with their lives so we may miss some people who would really benefit from such a meeting.

The Service of Remembrance is once again to be held in St Botolph's Church, Bishopsgate. This year the service will take place on Saturday 27th October at 3.00pm and will be followed by tea and an opportunity to meet old friends and remember loved ones.

If you know of anyone who would like to attend, please tell them about it.

REGULAR PAYMENT INCREASES

Last September the Trust was able to increase all monthly payments to registrants by £100 a month. We know that many of you have found the increase very helpful and that it has gone a long way to meet the real costs of living with HIV. During the months that the Payments Review Group looked at these costs, it was agreed that after the initial increase, Trustees would regularly review payment levels to ensure that as far as possible, payments would in future take account of inflationary increases in the cost of living.

The current rate of inflation as measured by official indices is slightly over 2%. In view of the fact that within the last two years there have been substantial increases to monthly payments, to adjust to anomalies in the system and allow for several years' inflation, in addition to the one off rise for everybody last year, it has been decided not to make any further payment adjustments at the moment. Trustees will continue to monitor the position, to take note of specific increases to the cost of living with haemophilia and HIV and to act appropriately, bearing in mind the financial resources available.

SINGLE PAYMENTS

The level of many standard Single Payments was also substantially increased last year to take account of inflation. At that time it was necessary to advise everyone that in future all Single Payments to registrants would be given in response to medical need. This does mean that we must have medical support for applications, and when considering applications, Trustees and staff will have to assess whether or not the person's health will suffer if the grant is not given. This greater stringency is difficult for us all, but if we are to continue to receive present levels of financial support from Government, we must manage resources with great care.

The recent Department of Health Audit of the Trust pointed out that our expenditure has increased by 12% in each of the past two financial years. They also made it clear that wherever possible, grants that can be made by other statutory agencies should be applied for before coming to the Trust for help. In practice, where budgets have become exhausted, or the time lag before a statutory grant can be given is unacceptable on health grounds, the Trust will step in, but applications for statutory help must be made first, where such funds exist. Please help us by contacting your Centre or Claudette, the Trust's Social Worker, to see if there might be statutory funding to meet your need before applying to the Trust.

NB: Single payments to dependant families do not need medical support.

Ann Hithersay
August 2001.

WOULD YOU LIKE A HOME VISIT

Since taking up the post of Social Worker in December, I have been doing home visits at the request of registrants. I have done a lot of travelling and am enjoying doing so as it means meeting and putting a face to the people I am in contact with on a day to day basis by telephone.

For some, the visits take on a practical form, for others however it is having someone to talk to about the isolation of their particular situation. Although I am not a counsellor I have a vast amount of experience in a wide variety of situations and my ability to listen and allow the individual to speak is renowned.

The feedback that I have had from my visits so far has been positive; which is why I am now doing this piece in the newsletter. I am available to come and see you in your own home on a one to one basis. So please feel free to phone, write or e-mail me at socialworker@macfarlane.org.uk and we can make the arrangements for a visit.

Claudette Allen
Social Worker

MFT E-MAIL ADDRESSES

Macfarlane@macfarlane.org.uk
Admin@macfarlane.org.uk
Socialworker@macfarlane.org.uk
Benefits@macfarlane.org.uk

Please do not use the post box address as this is seldom visited now. In future, please only use the full postal address.

Alliance House
12 Caxton Street
London SW1H 0QS

when mailing letters to the Trust

Hat Trick Group

Haemophilia, HIV and HCV... not the sort of hat trick you would ask for. The Hat Trick Group has been offering facilitated peer support for people living with and affected by these issues in London and the South East for the last year. I am a man affected by all of the above and run the group on a voluntary and independent basis, I am funded by Crusaïd and supported by the Haemophilia Society, THT Lighthouse and The Macfarlane Trust.

Apart from regular meetings held in West London, Hat Trick disseminates current information to over 140 people through the MFT confidential database. Meetings are topic based and recently issues covered included liaison with MFT and a presentation by Dr Paul Giangrande (Centre Director, Oxford Haemophilia Centre) on blood product safety. These events also give people an opportunity to get together in a safe place to have a chat, share experiences and maybe even have fun!

It is very important that anyone affected by these issues feels welcome, the group actively encourages partners, widows, girlfriends, boyfriends and all those affected to join in. If you have any questions or comments about the group, please contact **GRO-A** or Babs on **GRO-C** or E-mail: haemophiliagroup@GRO-C

GRO-A

Positive Women:

SETTING OUR OWN AGENDA

A two day residential conference
for women with HIV

Monday 15th – Tuesday 16th October 2001
Manchester

For further information contact:

George House Trust
77 Ardwick Green North
Manchester

M12 6FX

Tel: 0161 274 4499

Fax: 0161 274 3355

A Website for the Trust

In his letter, the Chairman mentions the possibility of setting up a website as an additional means of communication between the Trust and those it is aiming to help.

Websites are all the rage these days and we need to be quite clear about what ours would be trying to achieve. It is being examined as an addition to, but not a replacement for, existing things such as the Handbook and the Newsletter. The following outline of possible contents shows how it would include material that is, at present, found in both but there are other items that could also be included. It would also be possible to include news with more immediacy than is possible with the Newsletter.

A key feature of the proposal is that the website could give each beneficiary of the Trust easy, read-only access to his or her file. Access is open to all under the Data Protection Act, but this would make it easier to access than other available means. It would also then provide the means for any changes or corrections to be made more easily and quickly than is possible at present.

A SERVICE OF THANKSGIVING FOR THE LIVES OF ALL THOSE PEOPLE WITH HAEMOPHILIA WHO HAVE DIED AS A RESULT OF THEIR TREATMENT WITH CONTAMINATED BLOOD PRODUCTS

**SATURDAY 27TH OCTOBER 2001
AT 3.00PM**

**AT ST BOTOLPH'S WITHOUT BISHOPSGATE
BISHOPSGATE, LONDON EC2**

All are welcome

We shall once again be repeating a Ceremony when people are invited to write a message and light a candle, which they then bring up to the altar. If you are not able to come, you may send a confidential message, which we will place on the Altar for you and read out the name of the person remembered, as a candle is lit especially for them.

You may wish to have the name of your loved one inscribed in the Book of Remembrance, which is held in St Botolph's Church throughout the year. The Book contains the names of all those who have died whose families wish them to be recorded in this way. If you would like to add a name to the book, or you would like to send a message to be read out at the service, you should write to:

Mary Ann Tanner

GRO-C

(Only family members may ask for a name to be added to the Book of Remembrance, but friends may send messages and light candles for loved ones.)

It will be seen that two levels of security are proposed - a password that would restrict access to those who would rightfully have an interest, which is about 1,000 people; and an additional password, unique to (and chosen by) each of those people to provide individual access to individual database files. There is no magic or 'rocket science' about this sort of security, but it would make the site and, more especially, the database very secure.

Comments would be welcome from anybody, whether critical or favourable. Please could such comments be sent to the office by the end of September.

SUGGESTIONS FOR THE WEBSITE

General description:

2 buttons

General Enquiries - possibly leads to slightly fuller description with links to Haemophilia Society, DofH (if they wish), maybe others.

Members - leads to request for username and password, both known only to the registrants and other selected users; leads to site introduction with 8 or 9 buttons (if 8, possibly using MFT logo):

1. News - leading to news page(s)
2. Payments - leading to page with basic descriptions and buttons leading to:
 1. types
 2. rates
 3. procedures (including downloadable)
 - application form
 - medical form
 - specimen doctors letter
3. Benefits - with buttons leading to:
 1. news
 2. types
 3. rates
 4. tips on claiming
 5. other as specified by Benefits Adviser
 6. DSS waiver (inside Handbook back cover)
4. Other help available - buttons leading to:
 1. finance
 2. legal
 3. health
 4. other TBA
5. Administration - buttons leading to:
 1. staff names, pictures, descriptions
 2. Trustees names, pictures, descriptions
6. FAQ
7. Contact us - leading to e-mail link and list of addresses, telephone and fax numbers
8. Links - buttons leading to Society, DofH, Birchgrove, others TBA
9. Access to your file on database (for discussion) - requiring further password (unique to each registrant, possibly obtainable through system at each person's first log into this part of site, with some form of reminder facility available) and providing read-only access.