4

The Bulletin

1990 – No. 1

Patron, H.R.H. The Duchess of Kent

Member of the World Federation of Hemophilia
Registered Charity number: 288260

The Haemophilia Society
123 Westminster Bridge Road
London SE1 7HR
Telephone: 01-928 2020

Not Relevant

'We have a strong Society'

C.E.R.T. REPORTS ON OUR ORGANISATION

In the first issue of The Bulletin in 1989, the Chairman Revd Alan Tanner, wrote that 1989 *would be a time to reflect and a* time to plan. So much had happened in the Haemophilia Society during the 1980s that we felt we had to take stock to ensure that we could keep up the standards we had set for ourselves. The Chairman announced that the Charities Effectiveness Review Trust – CERT – would help us to do that by carrying out an independent survey of the Society.

We are pleased to report that *CERT examined the Society and* presented its report in August 1989. Since then, the report has been studied by the Executive Committee and the Council. (A full account of the report and the Society's response to it appears on p 8.)

ENCOURAGING

One of the most encouraging things about the CERT report was the statement on its first page – "It is clear the Society is active, responsive to members, effective . . . and has many of the hall-marks of success."

The CERT consultant saw his assignment as one "to do with a successful organisation, not one struggling to survive".

In November 1989 the Society held its first-ever Chairman's Conference. This replaced the annual group seminar. The Chairman invited the senior officers from each group to study the CERT report and, with the Executive Committee, draw up a plan for the Society for the 1990s. This proved to be an exciting, co-operative working weekend. By the end of the Conference we had agreed to:

★ give more resources to member services

★ give more resources to *group development*

★ streamline our committee structures

★ strengthen the Council's advisory role

★ develop our professional staff team

Many of CERT's recommendations have already been put into action. Others will take longer to implement because they require careful thought and planning. In future we must keep our goals in sight and set priorities for our work. *We must ensure that our income* is sufficient to let us carry our our work for the benefit of people with haemophilia. There is much to be done. What is clear is that we have a strong Society *which can go forward into the* 1990s.

We are sure that with the continued support of all our friends, we are able to meet the needs and improve the lives of people with haemophilia. The last words should be those of one of our faithful group officers, Mrs Joan Blomfield (Vice-Chairman of the Southern Group). During the Chairman's conference Joan summed up the mood of the Conference when she said "We have witnes*sed the rebirth of the Society*".

Not Relevant

Not Relevant

THE SOCIETY'S NEW TELEPHONE NUMBER AS FROM MAY 6 1990

071 928 2020

Not Relevant

The USA, HIV and Visas

In Bulletin No. 3 1989 we outlined the problems facing people with haemophilia (and especially those who are HIV positive) as a result of USA immigration policies. In particular this led us to the position where, as a matter of policy on our part, it was felt that we could no longer cross the US frontiers in a[illegible] way which involved the e[illegible]diture of Society resources. Regrettably this meant that we could not attend the June International AIDS Conference in San Francisco nor the WFH Congress scheduled to be held in Washington in August.

WFH have now confirmed that the Congress will go ahead in Washington in June 1990.

It has also been reported that the US immigration authorities, while still requiring knowledge of the HIV status of those entering the country, will no longer enter that information on passport documents.

This change has been achieved in part through the efforts of the World Federation of Hemophilia. This has been a significant advance and our thanks are due to Declan Murphy, Executive Director of the Federation and Alan Brownstein, Executive Director of the National Hemophilia Foundation, for their unstinting efforts which have helped to achieve this.

However, notwithstanding what has been achieved, the UK Society remains of the view that the very requirement to notify HIV status is wrong and as a result, it will not be possible for us to enter the USA. Not attending the Congress will be a matter of very deep regret to us as we explain in the text of the attached letter sent to the World Federation informing them of our position.

On 11 January the Executive Committee of the UK Haemophilia Society debated at length and in detail the current policy of the US government relating to immigration regulations for people with antibody to HIV.

At present, HIV infection is classified as a "dangerous disease" by the US government. This means that anyone attempting to enter the USA who has HIV or is suspected of having HIV can be refused admission unless they have obtained a "waiver" on their passport.

The Committee re-affirmed its belief that the US Congress policy is a basic infringement of civil liberties and human rights. While recognising the alterations to normal travel procedures which are to be made in relation to attendance at international health conferences, and applauding the influence of WFH in securing those alterations, the UK Society remains of the view that the basic policy is totally unacceptable.

Until the position is fundamentally altered the UK Executive Committee will not approve any expenditure of Society resources to fund travel across the US frontier.

It is a matter of deep regret that this firmly held ethical conviction will prevent the UK Haemophilia Society from participating in the 1990 WFH Congress, to be held in Washington DC, and the International Aids Conference, to be held in San Francisco.

The UK Executive Committee wish to make it very clear that the Society has been, and continues to be, an enthusiastic supporter of the principles of the World Federation of Hemophilia. The policy outlined in this communication is therefore aimed at securing a change in the laws of the USA and is in no way intended to damage the Federation. Indeed, we look forward to the day when it will be possible for all members of the international haemophilia community to meet freely once again.

We remain interested to learn the policy of each NMO in this matter.

Yours etc:
The UK Haemophilia Society
12 January 1990

Not Relevant

MAKING THE RIGHT CONNECTIONS!

In April 1988 we carried an article under this title in UPDATE. We thought it would be helpful to repeat the article with new staff names and duties included.

Very often people ring the office and insist on speaking to the General Secretary who, with the best will in the world, cannot deal with every call *and* do his job! The result can be messages left, call-backs made – only to discover that the matter could have been perfectly dealt with by someone else who had been in the building – and available – at the time of the original call!! Also, as time goes on and the demands on the Society grow, it is important to remember that someone else can possibly help you as well, if not better than, the General Secretary whose responsibilities are wide-ranging.

PAUL BURBA will, more than likely, answer your incoming call. He is the best person to decide who to put your call through to and he can take note of any change of address, member's orders for literature and give general advice.

HEATHER MAYNARD is the General Secretary's Personal Secretary and works four days each week. On those days a large number of David's calls will go to Heather in the first instance. She can deal with enquiries just as well as David can – so don't feel cheated when you are put through to Heather!

JONATHAN COOPER is our expert on HIV and AIDS issues. He has encyclopaedic knowledge of the field and is your person if your enquiry relates to this or welfare matters arising from the infection.

LINDA MATTHEWS is our administrative ace! Linda is the vital link between man and the computer and, in turn, our accounting, fundraising, payment of bills, Deeds of Covenant, subscriptions, travel for those attending meetings, and so on. She also looks after all matters relating to local Group finance – so for all those things, she is the person to contact!

JUDE McGUIGAN is as near to a despatch worker as we will ever get! He handles the majority of our outgoing mail – including member's literature requests – and travel packs, and so on. Jude may not be in the front line of dealing with telephone enquiries but he is closely involved with getting the information to you!

ALAN WEIR is a voluntary worker on Tuesday and Friday each week and he handles all non-member enquiries for literature, etc. All such enquiries must be received in writing – and he is very fully employed for those two days with that task!

DAVID WATTERS, the General Secretary, is responsible for the overall running of the day to day operation and for implementing the decisions of the Executive Committee and the Council. He travels the country looking after the wider interests of people with haemophilia and is very much concerned with our relationship with other organisations – ranging from the Government to Centres and Centre staff. He is a keen advocate for members at tribunal hearings relating to social security benefits, especially in relation to Mobility Allowance!

NOW: we do try to be available to answer the phone each working day between 9am and 5pm: this is not always possible!

ALWAYS be ready to tell the person answering your call the nature of your enquiry – this helps us to help you!

THINK BEFORE YOU PHONE! We can often give better advice in response to letters!!

PRISON PAINTINGS

Pictured at the prison art show (Update, January 1990) held at the Addison-Ross Gallery, are (left to right): Helen Cooper, Linda Matthews, Jonathan Cooper and Alan Weir. Over £2,000 was raised from the show.

THE OFFICE WILL BE CLOSED FOR STAFF TRAINING MARCH 13-14

The Liverpool Haemophilia Centre

Dr. C.R.M. Hay, M.D. MRCP, MRCPath.

The Liverpool Centre serves the whole of Mersey Region as far east as Lymm, Macclesfield and Crewe and as far north as Southport, and also provides shared management for people with haemophilia from North Wales. These patients also get an excellent service from Dr D Watson in Wrexham, Dr D Gozzard in Bodelwydan, and Dr Tom Korn in Bangor.

Haemophilia care in Liverpool has traditionally been divided between Alder Hey Children's Hospital and the Royal Liverpool Hospital, the patients graduating from the one to the other in their mid teens. Between them the two centres are responsible for the c[illegible]of about 130 haemophilic pa[illegible]nts.

Originally based on 'Topics' ward of the old Liverpool Royal Infirmary, along with other interesting and esoteric diseases, the Haemophilia Centre has for the past ten years been based on ward 7Y of the new Royal Liverpool Hospital, a ward devoted entirely to haematology.

This is unfortunately on the seventh floor, a source of complaint. For this reason during normal working hours the service has become increasingly centred on the ground floor haematology laboratories. Apart from the usual laboratories, this complex contains my office, and that of the haemophilia nurse counsellor and the coagulation registrar or S.R., all the secretarial staff, the c[illegible]room for storage of c[illegible]entrate, and a large clinical room next to the blood-bank. Out of hours, ward 7Y and our medical on-call team provide a 24-hour service, seven days a week.

The core team: Back row (left to right): Mike Calaghan (senior physiotherapist), Dave Patterson (senior MLSO), Alan Smith (chief MLSO), Phil McEvoy (senior MLSO). Middle row (left to right): Alison Jones (haemophilia nurse and counsellor), Dr. Charles Hay (Centre Director), Miriam Waite (senior MLSO). Front row (left to right): Janet Lamb (senior physiotherapist), Helen Rogers (social worker), Lilly Adu-Nsiah (departmental secretary).

(Other medical staff were away at the time of the photograph, and others got lost on their way to the photo-call!)

CHANGING STAFF

The past few years have been a time of great change for the Liverpool Centre. Through a combination of retirements, career moves, and the advent of HIV, almost all the staff have changed over the last three years, and additional staff have been recruited.

I moved from Sheffield to replace Dr. B.A. McVerry in May of 1987. Shortly after this we were lucky to acquire the services of two senior physiotherapists Janet Lamb and Mike Calaghan (who accompanied the British Olympic Team in Seoul as physiotherapist, and is at the Commonwealth Games in Auckland, N.Z. with the British cycling team). Professor Leslie Klenerman succeeded Professor Robert Owen as Professor of Orthopaedics in early 1988, and we established a three-monthly joint-orthopaedic clinic with him and his senior lecturer John Walsh later that year.

Also in 1988, the availability of HIV-related funds enabled us to appoint Alison Jones as our first haemophilia nurse/counsellor. Helen Rogers, our social worker started early in 1989 replacing a shared social worker.

Similar changes have taken place at Alder Hey where Dr. Lynn Ball was appointed as consultant haematologist in late 1988, and Sr Mackett has recently started as haemophilia nurse. Regular meetings take place between the staff of the respective units so that we can integrate and co-ordinate the service. *(Continued on facing page)*

THE SERVICE

As many patients as possible are maintained on home therapy. The availability of a fully mobile haemophilia nurse has made it possible to introduce even some of our older patients, who thought they were too old to learn, to the benefits of home therapy. Home therapy is delivered to the blood-bank nearest the patients home by Blood Transfusion Service transport and, in the case of difficulty, to the patient's home.

Unusual bleeds are assessed either in the centre or by Sr. Alison Jones in the patient's home. Long standing chronic problems are assessed in the follow-up clinic which takes place every Monday morning in G-clinic, or in the joint-*orthopaedic clinic with Professor* Leslie Klenerman, and his senior lecturer, John Walsh.

Most severe cases of haemophilia are reviewed every three months, and their wives or girlfriends are also very welcome. This clinic now occupies a handsome suite of five rooms offering both space and, where necessary, privacy. Apart from myself and the coagulation registrar/SR, the haemophilia nurse, social worker and one of the physiotherapists all come to each clinic, permitting a comprehensive multidisciplinary review.

The patients are examined by myself and by the physiotherapist. A sequential record of the range of joint movement and muscle girth is kept so that we have an objective *measure of the success or failure* of the physiotherapy and exercise schedules devised between us in the clinic. It also enables us to identify backsliders!

The same group of physiotherapists are responsible for both in-patient and out-patient physiotherapy and hydrotherapy. This ensures continuity of care and provides a valuable insight into the results of physiotherapy in our patients. It also makes it easier to select patients for joint replacement, since those who fail to comply with pre-operative physiotherapy are more likely to suffer a disappointing operative result. Patient motivation and post-operative exercise are as important as the surgeon's skill in *ensuring good joint function* following replacement.

Blood is taken at each clinic visit to monitor HIV infection, liver disease, and inhibitors, as appropriate, and the results of previous tests often discussed. Wives and girlfriends of HIV-seropositive haemophiliacs who wish to be are also tested.

The clinic also provides a valuable opportunity for me to bring the patient up-to-date and to discuss in privacy any problems directly or indirectly related to haemophilia or HIV. They may also wish to chat with Alison Jones or the social worker Helen Rogers, who is also our designated contact with the Macfarlane Trust.

Much of the counselling is carried out by our haemophilia nurse, Alison Jones, or by our *social worker, Helen Rogers, in* the patient's own home. Alison Jones spends on increasing proportion of her time, visiting patients all over Merseyside and North Wales. This is a very important aspect of the service. Patients are more relaxed and open on their own territory than in an impersonal out-patient clinic, and their wives are more likely to be present to take part in the discussion. This provides an invaluable link between the patient, his family, and the centre.

Wives of HIV-seropositive haemophilic patients are in a particularly isolated position. Often in full time work and unable to come with their husbands to the follow-up clinic, they are also often unable to discuss their problems with friends and relatives. We recently established a women's support group to help alleviate this situation, and those who go to these meetings tell me that they find them useful.

Wives, girlfriends and some mothers get together for a very informal meeting about once a month. Although Alison and Helen attend these meetings, the medical staff do not attend since this would tend to make them more formal, and their very informality seems to be the key to their success. Anyone living in our area who would like further information should contact Alison Jones on bleep 158.

Supporting this clinical effort are the staff of the coagulation laboratory supervised by Mr. *Alan Smith and Mr. Dave* Patterson, who provide a 24 hour service to monitor all aspects of blood product replacement therapy, and all the diagnostic techniques required to diagnose the various bleeding diatheses and thrombotic disorders, as well as carrier detection.

RESEARCH

Current areas of research interest within the department include the immunosuppressive effect of blood products, haemophilic arthropathy, HIV, factor XI deficiency and hypercoagulability in pregnancy.

THE FUTURE

We look forward to the installation of an integrated computer system for the centre in the Summer. This should improve our records and prescribing. There is still the need for more secretarial staff, and nursing staff, as our service matures, and we hope that we will not have too long to wait for this. The relentless expansion of clinical haematology has outstripped our ward accommodation, which is now inadequate, and plans are now in progress to upgrade it. With these developments, and with increasing experience, we hope to be able to provide an improving service in the future.

Not Relevant

HAEMOPHILIA NURSES

LINKS WITH THE HAEMOPHILIA SOCIETY
BY SISTER SHEILA HAYDEN

The London Hospital is a designated centre for the treatment and care of children and adults with haemophilia and von Willebrand's disease. Under the direction of Dr. Brian Colvin the Centre provides specialist nursing and medical care, social work support and domiciliary nursing care.

As Haemophilia Sister my role includes co-ordinating the in-patient and out-patient treatment and care of our clients. I took up this post in February 1989. My previous experience was in haematology/oncology nursing. As a newcomer to the world of haemophilia I [illegible]s keen to utilise all available [illegible]urces, one of the first things I did was to visit the Haemophilia Society and the Macfarlane Trust. These visits were extremely informative. I was pleased to make contact with David Watters and Jonathan Cooper at the Society and John Williams and Tudor Williams at the Macfarlane Trust.

In addition to receiving literature on haemophilia and HIV infection, I obtained patient information leaflets on a range of needs including attendance allowance, mobility allowance, insurance cover, and many more. My subsequent experience has been that the Society endeavours to back up its members with assistance with their applications for these matters.

As well as their initial support the Society has been a continuing source of information and support [illegible]myself and my clients through[illegible] the past year. I should also mention at this point the effective administration of the Macfarlane Trust which we find very responsive and prompt to deal with the financial needs of our clients who are affected by HIV.

PERSONAL AND PROFESSIONAL DEVELOPMENT

From a personal and professional development perspective I benefited enormously from attendance at a number of seminars organised by the Society. The most recent was that held at the London Lighthouse in November of last year. It was for carers, families and individuals affected by HIV; as always I was inspired by the courage and determination of those who attended.

(Ed: See page 12 for full report)

CAMPAIGNING FOR PAYMENT

I was impressed by the vigorous campaign by the Society on behalf of its members who are affected by HIV. I have seen considerable achievements in my first year as a Haemophilia Sister.

PATIENTS VIEWS

I think it is appropriate to consider how the Society is viewed by our Centre's clients. At a recent support group which was attended by a number of parents who are coping for the first time with haemophilia following the recent diagnoses of their sons, we had a general discussion on the benefits of Haemophilia Society membership. Subsequent to that meeting two of the mothers put their views in writing for inclusion in this article and these are set out below.

WORKING TOGETHER

A series of articles from those with whom we work closely

Mrs. GRO-A

My son, GRO-A is 18 months old. Two weeks before his first birthday he was diagnosed as having severe haemophilia A. I had spent two nights in hospital with him, and on the third morning we were visited by the Haemophilia Sister. We talked for an hour; numb with shock, I remember very little of what was said on that occasion, but I did take home a bundle of papers, leaflets and books on haemophilia, together with an application form for joining the Haemophilia Society.

Back row (L-R): Maggie Buckley (Children's Ward Sister), Shirley Walker (Clinic Sister), Dr. Roger Harris (Consultant Paediatrician), Dr. Brian Colvin (Centre Director), Peter Ellis (HIV Liaison Officer), Nigel Harvey (HIV Social Worker). Front row (L-R): Wanda Little (Domiciliary Nursing Sister), Sheila Hayden (Haemophilia Sister), Mary Ainworth (Chief Scientific Officer), Dr. Corinne De Lord (Haematology Registrar), Professor Jenkins (Head of Department), Jill Hicks (Secretary) and Rose Saville (Voluntary Staff).

It is very early days for us. GRO-A is still a baby and as yet has had very few problems. However, the Haemophilia Society has already proved to be a tremendous source of help. The textbook "Living With Haemophilia" was read avidly and now sits on our bookshelf in the lounge. It is well thumbed already and no doubt it will be referred to time and again in the future. In practical terms, the Society has already helped with holiday insurance, and in the next few months I expect I shall need guidance on applying for attendance allowance. Also, the Bulletin is of great interest.

There is no history of haemophilia in our family, and this can lead to a sense of fear and isolation. It is therefore a great comfort to read articles that are written by people with haemophilia and those who care for and about them, and to know that those who suffer from this condition do cope with normal everyday life. And when we read about people with haemophilia who are HIV positive, we count our blessings, in the knowledge that if our son had been born five years ago, our situation could have been much worse.

We know that in the future we are going to take a great deal from the Haemophilia Society, and it would be all too easy to do so without giving anything back. But "Working Together" means doing something in return as a token of appreciation. For our part, we managed to sell nearly 250 raffle tickets for the Christmas draw, and in the New Year my husband will be setting up a Deed of Covenant for the Society. We feel that this goes some small way towards thanking the Haemophilia Society for being there.

Mrs. GRO-A

Our son, GRO-A who is now two, was diagnosed as having severe haemophilia when he was eleven months old. It came as a great shock to us as there is no history of haemophilia in our family. We later found out that I GRO-A's mum, am a "carrier".

On finding out about GRO-A's condition our Centre Director, Dr. Colvin from The London Hospital, Whitechapel, strongly advised us to get in contact with the Haemophilia Society. We immediately joined the Society and in the past year we have been registered with them, they have supplied us with valuable information and regular updates on the subject of haemophilia and other blood conditions. On joining them they supplied us with a book "Living with Haemophilia" which has been read dozens of times and has helped also to widen our knowledge on the condition.

At the present moment we are attempting to claim Attendance Allowance for GRO-A and have been grateful to the Society for supplying us with a letter of support to back our claim. We have heard from other parents that they run a very successful holiday each year for children over seven years old and we look forward to sending GRO-A in the future, on one.

The help and information that they can give is an endless list and although we have not yet had the need to use the facilities they offer to the full, we are extremely grateful to them for being there and knowing that whatever problems we may come across in dealing the GRO-A's condition, they will be there to help us.

THE CAMPAIGN: PUBLICITY AND YOU

by GRO-D

Over the last few months, there has been a considerable amount of coverage in the press and broadcast media about the campaign for compensation for HIV infected people with haemophilia. During this time I have been personally involved as the subject of a number of interviews and features, and the purpose of this article is to try and pursuade other members to share the load, and be involved on the same basis.

It is, of course, of primary importance to educate interested parties such as MPs. and civil servants, as well as the general public as to the tragedy of our situation. Despite the impeccable presentation of our case by the Society, nothing captures the imagination like a "human interest" story, and the greater the number of our memb[illegible] who are willing to be involved, the better our chances of influencing the Government.

You may be worried as to the effect that involvement with the media may have upon your own personal life. Will their representatives be sympathetic to you and your difficulties? What effect will it have on the relationships between you and your immediate family and friends? Will you find discussing your problems personally disturbing? From my personal experience, these worries, which I certainly had intitially, will be largely groundless.

ON OUR SIDE

Firstly, contrary to the populist view, the ladies and gentlemen of the media are fair-minded people. Every request I have made during an interview for a discretion, usually regarding the restriction of the use of my children's names, has been adhered to. Interviewers have always asked whether they can mention subjects that one might find too difficult or painful to discuss. They will always be sympathetic to requests. Remember, like most intelligent, fair-minded people, they are on our side, and want to show us in a favourable light.

The major worry for most people is the effect publicity will have in the workplace, or in the school, and the comments or discrimination that might consequently occur. I should like to make the following points:–

1) We have done nothing of which we should be ashamed!!! We did not ask for this situation to happen, still less were we knowingly involved with high risk infectivity activities.

2) He who condemns us condemns himself by either ignorance of stupidity.

3) Discrimination thrives in an atmosphere of secrecy and fear. Publicity withers it away.

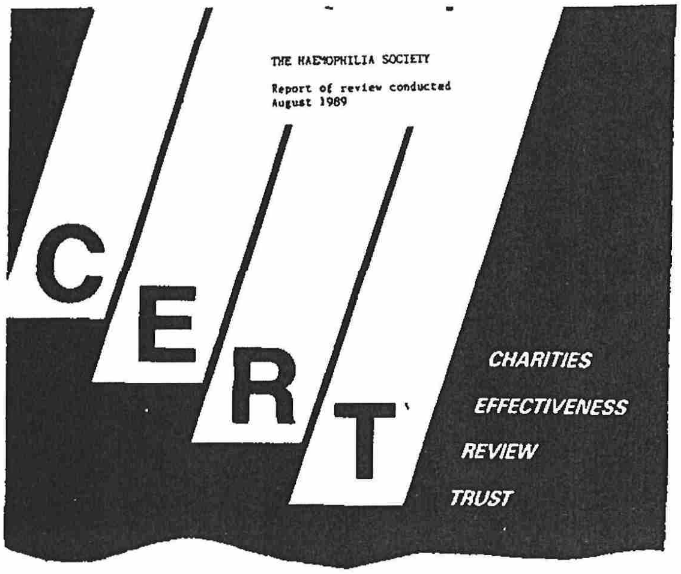
You will be surprised, as I have been, at the many wonderful people who, either unknown, or from the past, come forward to pledge their support. You will find, contrary to your first fears, the publicity will help you, as well as others. Please therefore, let us have your help.

Ed: See Letters Page 15.

Not Relevant

The Society's first Chairman's Conference maps out our route into the 1990s

THE CERT REPORT


THE HAEMOPHILIA SOCIETY

Report of review conducted
August 1989

CERT

CHARITIES
EFFECTIVENESS
REVIEW
TRUST

It is a mark of a mature organisation that it can look critically at itself and make changes to its structure and way of working.

The Haemophilia Society has had to adapt to great changes in its tasks and responsibilities. Changes have been made in order to allow the increased workload to be dealt with. At the start of 1989 it was clear that if the Society was to be fit for the 1990s, a more thorough review of our operations was necessary.

During the first half of 1989 the Society engaged the Charities Effectiveness Review Trust – CERT – to carry out an independent study of our organisation. The consultant's report was delivered in August 1989 and studied in detail by the Executive Committee in September and October. The Council spent a weekend in November considering the report and the Executive Committee's recommendations, and determining a new way of working to equip the Society for the challenges of the 1990s.

THE REPORT

The job of a management consultant is to hold up a mirror to an organisation so that the organisation (or those who manage it) can see itself as others see it.

Very quickly, CERT acknowledged that the Society has been, and is, effective, active and successful in meeting the needs of people with haemophilia. CERT and the Society agreed that the *main purposes of the review* should be to:

★ examine the way the Society makes decisions

★ consider the contribution and role of those elected to run the Society

★ consider the arrangements for planning and administering the Society's finances.

The CERT consultant embarked on a series of meetings with members of Groups, Council and the Executive Committee as well as representatives of the medical profession. This enabled the consultant to get a broad spectrum of opinion about the Society and its work.

'A number of strengths and weaknesses'

The report which was produced as a result of these meetings, and the consultant's skill and experience, identified a number of strengths and weaknesses in the Society.

The good points which were highlighted in the report are the Society's willingness to adopt new ideas and challenges, our willingness to take risks, and the ability to be innovative and forward looking. The positive leadership given by the Chairman and the General Secretary was praised, and this dynamic combination of leaders was identified as being one of the most important factors in the success of any charity.

The areas where CERT felt the Society should apply more thought and attention include the constructive resolution of the conflict which can sometimes exist in the most healthy organisations. (There have been occasional differences of opinion in Council meetings!) Where there is conflict it should be recognised and focussed as a source of energy to lead the Society forward. The Society was gently warned not to regard the past with too much "nostalgic self-satisfaction". Finally the Society is encouraged to be aware of the importance of setting specific targets and objectives. Only by knowing where we are going can we be assured of making progress towards our goals.

The report included much detailed analysis of the ways the Groups, the Council and the Executive Committee work. It made a number of suggestions about the ways in which improvements could be achieved.

In general it is not part of the management consultant's work to tell an organisation what to do next. The CERT report was no exception. If a review is to be worthwhile those who are responsible for running the organisation must be committed to making improvements and carrying them through. Therefore the Executive Committee and the Council of the Society devoted many hours of study to the report and to working out ways of implementing its recommendations. Some of CERT's advice has already been put into effect, some of its recommendations have been accepted for the future and some of its suggestions have been adapted to suit our own particular ways of working. The remainder of this article describes the new systems which the Council and the Executive Committee have agreed are needed to lead the Society to greater success in the next decade.

MEMBER SERVICES

A great deal of time and effort is already given to dealing with requests for help and advice from individual members. However, this aspect of the Society's work is increasing. A commitment has been made to devote more staff resources to assessing and meeting members' needs.

New procedures for processing requests for financial assistance (formerly dealt with monthly by the Case Committee) are now in operation. This has already resulted in a much faster response in cases of need.

GROUP DEVELOPMENT

The proposal in the CERT report relating to Groups was clear and concise: abandon them or nourish and foster them.

'Abandon groups – or nourish and foster them'

There is unanimous agreement that Groups have a vital part to play in the Society because of their local contact and knowledge. The contribution made by Groups to the work of the Society will be developed by making more staff resources available to Groups. This will enable the Society to strengthen Groups through training, education and services.

MANAGEMENT

CERT recommended a complete overhaul of our organisational structure, committees and decision-making.

The Council remains as the consultative forum where local Groups exchange views and discuss with the Executive Committee the strategy of the Society.

The Executive Committee is committed to reducing the number of meetings of the full Committee and delegating more responsibility to new sub-committees to ensure

(Continued on facing page)

Not Relevant

that its increased work-load is managed effectively.

STAFF

The implications of the changes outlined above are that the Society will need to examine the way the present staff team can be organised to provide the improved member and group development services. It may be that additional staff will be necessary in the future.

'Committed to making improvements and carrying them through'

The Society recognises the value of professional staff in meeting the needs of our members. The Society is committed to improving staff training and ensuring that our responsibilities as an employer are met fully.

FINANCE

The Society has recently made great improvements to our financial planning, reporting and control systems. A part-time fund raiser was employed in 1989. This appointment has allowed the General Secretary to concentrate his efforts on other aspects of the Society's work. Greater emphasis will be given in future to matching our planned level of services (and hence expenditure) with our targeted income. The ultimate key to this lies in establishing the priorities in each area of the Society's work.

'Completely overhaul our management structure'

THE FUTURE

At the Chairman's Conference in Newcastle in November, the Group delegates and the Executive Committee discussed all the issues contained in the CERT report. An atmosphere of enthusiasm and unity made this one of the most memorable events in the recent life of the Society. The decisions made at the Conference mark the start of a programme of development and growth which will take time to come to fruition.

We will all have to learn new ways of working, new ways of meeting the challenges which lie ahead of us. With the new structures and the renewed dedication of our members and staff we can look forward to the 1990s with confidence and optimism. We are proud to endorse the statement made at the Conference by Mrs Joan Blomfield, Vice-Chairman of the Southern Group, "we have witnessed the rebirth of the Society in 1989".

'The rebirth of the Society'

Footnote:
The Chairman, Officers and Executive Committee would like to place on record their thanks to all who participated in the preparation and discussion of the CERT report.

Not Relevant

Not Relevant

CHOICES FOR THOSE LIVING WITH AIDS

by Dr Veronica Moss and Ruth Sims

Surveys seeking to answer the question 'Where do people die?' have revealed that the majority of people suffering from life-threatening illness die in hospital.

A recent survey of AIDS-related deaths made by Ann Kennedy (Public Health Laboratory Sciences Unit, Communicable Diseases Surveillance Centre) showed that 83.4% (out of 362 surveyed to end of 1987) died in hospital, 15.2% at home and 1.4% in a hospice. This was before the opening of Mildmay's AIDS Hospice and Continuing Care Unit in February 1988 and Lighthouse's Residential Unit in September 1988.

A more significant question perhaps should be, 'Where would people choose to live until the time comes when they have to die?'. The choices open to people living with AIDS is still very limited. People often choose to live and die in hospitals because these provide a greater sense of security than that which is available for them in the community, in their own home. They may be afraid of going into a hospice since the word hospice often has such a final ring to it.

OPTIONS

The options for care available in a hospice or continuing care unit are often not fully understood, and it is well known that the community services are already fully stretched and inadequately funded. Traditional hospices may be unwilling or unable to admit people with AIDS, although many are now addressing the issues involved. People fear also the attitudes they may have to face in health care professionals and those working with other statutory services such as home-helps.

In some parts of London these issues are being addressed, and education is changing the attitudes of statutory and voluntary services in these areas. However, what of the many parts of the country where this is still not so?

When Mildmay Mission Hospital opened Europe's first AIDS hospice unit in February 1988, the need that had been identified, in discussion with local Health Authorities, Frontliners, Terrence Higgins Trust and others, was for terminal care. Mildmay's accent was very much on living with AIDS, on control being given back to the patient, and on high professional standards of care.

TEMPORARY RECOVERY

Some who were admitted to Mildmay for terminal care recovered, albeit temporarily, and we quickly found ourselves having to provide rehabiltative, convalescent and respite care. On analysis of the first 100 admissions we found that approximately 40% were admitted for terminal care (approximately 9% were for long-term care, i.e. more than three months), while 32% were for rehabilitative care, and 28% for respite care. Three of those who were admitted for short term terminal care recovered and were able to go home or to sheltered accommodation, one needed long-term terminal care for more than three months, while others made temporary improvements for some weeks with good symptom control.

We received a number of referrals who were not admitted for long-term terminal care, or long-term supervisory care: services in the community were totally inadequate to enable them to remain at home or even in sheltered accommodation. Because of the pressure on beds our policy is to take only a limited number specifically for long-term care.

With the continuing spread of the epidemic and with our increasing expertise in treating opportunistic infections and other AIDS-related problems, increasing numbers of people will require long-term supervisory care or accommodation which is adapted to fit the needs of people with chronic illness or disability. More and more people will require support or facilities at home which will enable them to stay there as long as possible.

CHOICES AT MILDMAY

Rehabilitative or convalescent care is aimed at enabling people, who have had a serious or acute illness requiring treatment in hospital, to return to independent living. The care provided at Mildmay is through an interdisciplinary team including nurses, doctors, physiotherapists, occupational and other therapists, counsellors, chaplains and welfare services. Frontliners has an office at Mildmay and provides support, housing, legal and other advice. The emphasis is on promoting independence.

Respite care is provided for those living at home but who need a break themselves, or whose carers need a break. This admission may vary from a weekend to up to four weeks. Here there is also an emphasis on living and on rehabilitation, of giving back control to the patient to promote greater independence and quality of life.

Terminal care is provided through the same team and the emphasis is on quality, dignity and peace for the patient and full support for the partner, family and friends.

To widen the choices available to people living with AIDS, Mildmay opened on 6 November 1989 a *Continuing Care Unit* with eight single rooms to provide longer-term care as well as the above categories of care. On 31 October 1989 a *Day and Home Care Service* was started. These will enable people to remain at home and are, of course, mainly available for people living in Tower Hamlets, City and Hackney and Newham. London Lighthouse provides their own range of facilities for people living in the West End of London. Statutory and voluntary services such as ACET and their home care team, together with several home care teams being set up from the main centres of excellence such as Bloomsbury Home Care Team and St Mary's Hospital Home Care Team, are now enabling a greater choice to be given to people with AIDS who wish to live at home. However, there is still a very great gap in the services and accommodation available for people with the more chronic and long-term problems.

CHOICES FOR WOMEN WITH CHILDREN

Our consumer research has revealed that there is an increasing and strongly felt need for respite care which provides for the whole family unit, in particular for mothers with children who may or may not have AIDS or HIV. A mother with AIDS may well be finding that her home is a prison; she has few supporting services available to her with her own increasing health problems and concern that the children should not have to go into care. The difficulties that many women are facing are enormous. Many feel extremely isolated and lonely, facing the same rejection or fear/phobias from their neighbours, family and friends, as well as from health care professionals and statutory services, with which others with AIDS are so familiar. What choices do they have? One woman required acute care for herself but was unwilling to allow her child to go into care and therefore could not agree to admission for herself to an acute unit. The only solution that was available for her in the end was to be admitted to a paediatric ward which would also accommodate her child.

Mildmay does not provide acute care, but in order to respond to the present and growing needs we plan to furnish a two-roomed family suite as part of the Tankerville unit. This will be ready for use by the end of the year. Facilities are being planned for the care of well children accompanying their mother, thus enabling the family unit to remain intact, with accommodation, where appropriate, also being provided for the father.

NUMBERS ARE SMALL

The numbers are still, thankfully, small but the needs are felt acutely now. In order to give women real choices it is essential that plans are made, and quickly implemented, for provision of respite, convalescent and terminal care facilities for women with children.

Sadly, it will not end there: long-term care of children will also be required, with plans and preparations made for fostering and adoption of children who have parents too ill to care for them; or whose parents have died.

Most Health Authorities have appointed, or are planning to appoint an HIV-coordinator. In some areas the local authorities are doing the same, or have joint appointments with the Health Authority. This will go a long way towards helping to coordinate and plan services for an area, but much planning as well as funding, with education and training, is still needed if we are to enable people with AIDS to have any degree of choice as to where they are to live with AIDS.

Dr Veronica Moss is Medical Director and Mrs Ruth Sims is General Manager of the Mildmay Mission Hospital in London.

QUIZ ?

Basic Information: Living with Haemophilia

The following questions deal with haemophilia in general. Not all of them will apply to you directly.

Multiple Choice

In the following questions please place an X before each correct answer. There may be more than one correct answer for each question.

EXAMPLE:
Haemophilia is:
[illegible] _X_ A genetic blood clotting disorder.
b. ___ A tropical plant.
c. _X_ Very rare in girls.
d. ___ I don't know.

1. Symptoms of a joint bleed are the following:
a. ___ pain
b. ___ nausea
c. ___ stiffness
d. ___ cold
e. ___ heat
f. ___ not sure

2. Factor concentrates:
a. ___ control or stop bleeding.
b. ___ contain clotting factor from normal blood.
c. ___ should only be used in extreme emergency.
d. ___ not sure.

3. Use of factor concentrates sometimes can cause:
a. ___ hepatitis
b. ___ diabetes
c. ___ allergic reactions.
d. ___ not sure.

4. When a person thinks that he is beginning to bleed into his joint the ONE MOST IMPORTANT thing to do is:
a. ___ apply ice and bandages.
b. ___ wait and see if the bleeding will stop by itself.
c. ___ infuse with a factor replacement material.
d. ___ take pain medication.
e. ___ not sure.

5. The reason(s) a patient with haemophilia should wear a medical I.D. tag or bracelet is/are to:
a. ___ alert his friends that he has a medical problem.
b. ___ alert medical personnel when the patient is unconscious.
c. ___ remind the patient that he can't do things that other people do.
d. ___ not sure.

6. A person with haemophilia should:
a. ___ eat a balanced diet.
b. ___ avoid all exercise.
c. ___ exercise regularly as directed by his doctor.
d. ___ take vitamin K supplements.
e. ___ not sure.

7. A person with haemophilia should keep a record of bleeding episodes and treatment for the following reasons (s):
a. ___ It is an important part of his *medical history*.
b. ___ To remind him that he has a problem.
c. ___ So that the physician responsible for his care can supervise him properly.
d. ___ *not sure.*

8. Factor replacement therapy is USUALLY necessary in the following situations:
a. ___ *joint injury.*
b. ___ head injuries.
c. ___ dental extractions.
d. ___ abrasions, such as a scraped knee.
e. ___ nose bleed.
f. ___ not sure.

TRUE OR FALSE

Circle the answer appropriate to the following statements, (T) True, (F) False, or (U) Unsure:

9. T F U
A person who has haemophilia bleeds faster than a normal person.

10. T F U
When haemophilia is passed down from one generation to another the severity of the disorder usually varies from one individual to the next.

11. T F U
If carriers of haemophilia were prevented from giving birth to children the disorder would become extinct.

12. T F U
All females born to fathers with haemophilia will be carriers of the disorder.

13. T F U
Persons with haemophilia should be allowed to participate in most normal activities.

14. T F U
Aspirin and factor replacement therapy are recommended for painful joint haemorrhage.

15. T F U
Regular tooth brushing and flossing are important for a person with haemophilia even if it causes some bleeding of his gums.

16. T F U
Some patients outgrow haemophilia.

17. T F U
If a patient with haemophilia has received a recent dose of factor material it is not necessary for him to wear a seat belt in the car.

(Taken from HEMOPHILIA TODAY', the journal of The Canadian Hemophilia Society.)

Not Relevant

ANSWERS

1. a, c, e
2. a, b
3. a, c
4. c
5. b
6. a, c
7. a, c
8. a, b, c, e
9. F
10. F
11. F
12. T
13. T
14. F
15. T
16. F
17. F

Not Relevant

A one-day workshop for families and carers

Families affected by HIV and AIDS

Rosie Claxton, Children's Nurse and Counsellor, Terrence Higgins Trust

It was a special experience to be part of a mixture of people who came from many parts of the UK some from the very real frontline, living day and night with HIV and AIDS. Some were partners, relatives and friends of those who have the virus. The rest were those involved in either the statutory or voluntary services where HIV and AIDS are also part of their lives.

The workshop was about building support systems and was organised jointly by the Haemophilia Society, The Terrence Higgins Trust and London Lighthouse. There was a noticeably refreshing change from the usual facts, figures and [illegible]ational input that has become part of the framework for conferences and workshops about HIV and AIDS. This day was about choice, feelings and opportunity.

A FATHER'S STORY

The morning started with a father telling of how he and his family are coping from day to day with a boy with haemophilia who has been ill with HIV for a long part of his short life. He described the hopelessness, anger and fear that go together with HIV and AIDS, and how he and his wife had been thrust into the role of carers.

He gave a powerful description of how it feels "having to continue to play a game that they know they can never win, there are no reserves in the team". His son spends progressively more time at the hospital unable to understand why he isn't well enough to enjoy life with his friends. He told us of the local support group, explaining how the recent death of a child had affected them.

The joint strength of the group was available for them to draw on whenever it was needed.

Following on from this, a mother told of how she discovered that her son was gay, a schoolboy who was struggling to cope alone with isolation and rejection from colleagues and professionals alike. She realised that the taboos surrounding sexuality are unaddressed by most who work with young people. Her personal experience led her to form a support group *for parents of gay and lesbian* young people in the North of England.

The group is successful as there is a place for parents to meet, share their thoughts and feelings in a non-judgemental and accepting atmosphere. There are many problems in having to support youngsters in a world that is yet to understand how it feels to be 13-years-old and homosexual.

WORKSHOPS

An hour of workshops followed. The subjects were about self help, voluntary and statutory support for families, with specific reference to: those with children, those with drug users, black families, haemophilia, partners, alternatives to group support and bereavement. (It would have been helpful to have included a question and answer session on medical matters.) Many found one short hour was too little time to *share thoughts and feelings,* perhaps next time.......

The afternoon started with Dr Pat Hartley describing how families of people with eating disorders have been helped by a self-help support group. She hoped that the model used might become appropriate for those affected by HIV and AIDS. The support was initially run as a helpline and has now grown into a more structured support group.

Three members of the Terrence Higgins Trust Family Support Network then described their work. A father, whose son with AIDS died 4½ years ago, told of the feelings of total isolation he realised others must share, in a similar position. He and his wife joined with the Trust and started a telephone network that is available to relatives (and friends) caring about people with HIV and AIDS.

He told of how he was invited to run workshops: these had previously meant woodwork and places where practical D.I.Y. things happen. GRO-D and GRO-D explained the monthly meetings for families and told about other support groups available through THT. GRO-D GRO-D added that there are many groups available at London Lighthouse.

Following on, Juliet Swindells (AIDS Counsellor) described the work that she and Dr Mark Winter are involved in, in darkest Kent (Margate, Isle of Thanet). There is a range of support there for all those who live with HIV and AIDS. This work started over four years ago, when it realised that there was need for help from others, outside the hospital. This help is now given by teams of people who are part of the local *Body Positive group, together* with volunteers who work with Thanet Association for the Terminally ill – TATI for short! There is now home care, practical support, an AIDS helpline and other services provided whenever and wherever it is needed. There is also a plan to build a home for homeless people and families with HIV and AIDS, a much needed project; there is a plea for funding, as this is urgently required.

GROUP DISCUSSIONS

The day ended with groups from regions meeting to discuss the possibility of setting up national support systems. A parent suggested that there is still a large barrier between the professionals and people and families living with HIV and AIDS. Another said that she would welcome a 'phone call from someone who would just ask "How is it going?"'. It was also felt that professional 'jargon' also acts as an obstacle. Many people gain some degree of support in different ways, what is helpful to one person may be unhelpful to another and choice should be given to the individual. This day, may enable those to give and receive support that is appropriate and available when it is needed. Hopefully too, there may be further opportunity for those whose voices weren't heard on this day to be heard when the time and place is right for them.

Grateful thanks are due to the organisers. This was the first joint venture between the agencies who provided space and time for meeting old and new friends, a *good lunch, and despite the* power-cut, London Lighthouse was an ideal setting. Experiences were shared and foundations laid for planning an effective support system for families and carers.

Not Relevant

Not Relevant

NUTRITION – THE NEGLECTED KEY?

by GRO-D

FROM: Body Positive Newsletter – Issue 80 – 24 Oct. 1989

Recently The British Society for Nutritional Medicine held a two day symposium called 'Nutrition, Immunity and AIDS'. Sadly this excellent organisation for doctors has only about three hundred members nationwide and only about eighty-five people attended this conference.

Professor Chandra (Memorial University of Newfoundland, Canada) started by noting that the effects of nutrition upon immunology were noted in Indian literature as early as the twenty-fifth century B.C.!! Malnutrition, he pointed out, can occur with quite moderate deficiencies in diet. Tuberculosis, measles, pneumocystis carinii, trypanosomiasis and candida are definitely the result of poor nutrition while diseases like diphtheria, influenza, malaria and AIDS are possibly caused by poor nutrition. It is important to remember that consuming the right foods is not enough – the important thing is whether the nutrients consumed are being properly absorbed by the body.

ABSORPTION PROBLEMS

Many people with severe HIV infection have absorption problems which causes the weight loss which is so obvious in advanced cases. It is not that they are eating too little or the wrong foods but that the body cannot benefit from the foods consumed. The importance of vitamins and nutrients A, C, B6, E, Zinc, Selenium and Arginine were stressed. Importantly, the dangers of over-dosing were also mentioned.

Dr Brighthope, an Australian, who had a background in agricultural science before entering medical school, started with the sad fact that some patients enter hospital better nourished than when they leave. He listed those factors which inhibit the immune system – drugs, tobacco, alcohol, poor nutrition, obesity, negative mental attitudes and a sedentary lifestyle. He also made the obvious point that individuality is a crucial factor in nutrition. What reacts well with your body may not with mine. In terms of nutrition he started with sugar. In 1900 the average Australian consumed 2lbs of sugar a year, today the figure is 120 lbs. (Presumably British figures are similar.) Sugar consumption, of course, is not simply the spoonful that you put in your tea and coffee. Look at the ingredients of the vast majority of tinned or prepared foodstuffs and sugar, in one form or another, is present. He next turned his attention to food additives and preservatives which he described as "the greatest uncontrolled experimentation on mankind in history". His main thrust though was on the importance of Vitamin C which inhibits the growth of viruses, helps interferon production in the body and is useful for patients receiving chemotherapy. So long as the rest of the diet is balanced it should also increase 'T' cell production. He gives his advanced patients intravenous ascorbate.

OTHER THERAPIES

Brighthope also emphasised in his second presentation the importance for some patients of visualisation, homoeopathy, herbalism and other alternative/complementary therapies. He also, to my mind, rather gloomily referred to Martinez's comment in *The Lancet* in March, 1988, that 'all the important determinant events for the outcome of the infection occur before contact with the virus'.

When a patient presents with well-advanced HIV infection he starts with what he describes as an 'Acute Phase' diet which is largely macrobiotic and may be taken in liquid form ('the astronaut diet'). Dairy products are avoided. The patient then progresses to the 'Maintenance Phase' which may include fish, meat and possibly dairy foods. A normal patient at this stage is given 1-4g of Vitamin C a day, if the patient is having to cope with stress the dose is increased to between 4 and 10g while if the patient is very ill 15-60g of ascorbate will be administered. In addition he prescribes between 50 and 200 micrograms of Selenium a day. Some of his patients use raw juices while he recommends that his patients cut back on alcohol, tea, coffee, and chocolate. As part of his anti-Candida regime he uses Acidophillus, garlic, olive oil and biotin. Amongst the herbs he uses are mistletoe, red clover, chaparral, aloe vera, comfrey, wheat grass and echinacea.

PESTICIDES

Professor Rea from Texas spoke about the effect of pesticides upon the immune system. In a convincing display of statistics he showed how pesticide use has increased while land usage in agriculture has fallen in the United States. This has caused, he argues, the rate of cancer in an agricultural state like Iowa now to be as high as that as New Jersey where with pollution and industry the rate has always been high. At the other end of the scale he quoted a tribe in South America near the Andes with few outside influences where chronic illnesses do not occur because there are no pesticides and where one is far more likely to die of a snake bite or a spear wound! The effects of pesticides upon 'T' cell counts were easy to show.

Christine Baldwin who is a dietician from Camberwell talked about the dietary management of patients. She impressed the importance of giving each and every patient a nutritional assessment and argued that an aggressive approach to nutritional therapy should be pursued at all stages of the disease to both maintain and improve the nutritional status of the patient while increasing the sense of well-being of the patient. She emphasised the fact that a multi-disciplinary team approach is needed.

IMBALANCE

In his second paper Professor Chandra who was a member of President Reagan's Task Force on AIDS Group on Nutrition noted that nutritional imbalance occurs early in the progress of HIV infection and that impaired immunity leads to infection and is itself worsened by that infection.

The objectives of the physician should therefore be to preserve lean body mass, provide adequate levels of all nutrients and minimize symptoms of malabsorption. He believes that nutrition has a partial effect upon HIV and AIDS although as yet there is little objective evidence to support the theory that progression can be slowed by good nutrition. (This is obviously difficult to prove as it would need to a control group to whom one denied nutrients to prove that they work in another group while allowing the health of the control group to suffer. In addition, unless one was prepared to lock ones "guinea pigs" up in a room it is very difficult to monitor everything they consume – half a mars bar, the odd cup of coffee, etc, etc.)

Looking at the problem from the other end as it were Professor Chandra noted that amongst people who had reached 'CDC II'I (what is also referred to as ARC) the following deficiencies are to be commonly found – vitamins B6, B12, Folate, Zinc and Selenium.

The message of the conference is that while not all the answers to AIDS lie in nutrition alone its importance should not be underestimated. The fact that the drug companies are for obvious reasons not putting many resources into looking at the nutritional aspects of the disease clearly has influenced the relative paucity of research that has been done.

I was impressed by almost all the speakers, but one kept getting the feeling that they were knocking their heads against brick walls. Brighthope spoke of the difficulty of getting state funding in Australia for more work on Vitamin C. Cathcart's work in America and his lack of funding has been discussed elsewhere. A simple rule of thumb is that you should consume *less* alcohol, tea, coffee, chocolate, dairy products, sugar, and cholesterol laden food and *more* fresh vegetables, fresh fruit, and live yoghurt. If you are thinking of taking vitamin supplements you should seek advice first.

Not Relevant

Letters TO THE EDITOR

JOHN PROTHERO

We have received a multitude of letters paying tribute to John Prothero and expressing condolences to Sharon his wife and his mother. This letter, from ANGUS KING, Medical Correspondent of The Yorkshire Post typifies much of what was said! All letters received will be given to Sharon in due course. In the meantime readers will be interested to learn that over £8,000 has been received in John's memory.

Sir:

I was so sorry to have heard, recently, of the death of John Prothero. I had a long period of contact with John in the 1970's when he gave me much valuable assistance to launch the Yorkshire Post's campaign on treatment for haemophiliacs in this country.

In spite of his own difficulties he was always cheerful and a great source of inspiration for the detailed articles which we were preparing. As you know, the result of the campaign was a great success resulting in more money being made available by the Government and the articles won the Campaigning Journalist of The Year Award in 1975. This success was in no small measure due to the contribution and persistence of John.

I shall remember him with great affection.

Yours etc:
Angus King
Medical Correspondent
'Yorkshire Post'.

Thanks for the privilege

Sir:

I wanted to write to the Society to thank you all for the privilege in allowing me to take part in the recent campaign for compensation. I also wanted to reassure members that 'going public' about HIV infection and haemophilia is not, in my experience, something to be feared.

For several days I appeared on television, in newspapers, and took part in radio programmes and everyone knew who I was, where I lived, where I worked and so on – and, this is really important, I received nothing but sympathy, compassion and support from everyone who came into contact with me.

For myself, I must also add that there was an enormous amount to be gained by talking openly: gone were all the pressures and tensions that had built up inside and I became relaxed and very much easier about myself and other people's attitudes to me.

I know that everybody's circumstances are different and having children who are at school could be a very real obstacle to going public. **But don't invent obstacles** that are not there – other than in your own mind!

By being open you will work wonders for yourself – and for the education of the whole community which must be taught to take HIV and AIDS seriously.

Yours etc:
GRO-A
Oxford.

Congratulations

Sir:

We have received your "THE BULLETIN", 1989, No. 3, for which we thank you very much.

We wish to congratulate you on the quality and importance of the articles published in this Bulletin, a real Update on haemophilia problems.

Yours etc:
Vitalina J. B. Dias da Silva
President
Federação Brasileira De Hemofilia.

THE SOCIETY'S NEW TELEPHONE NUMBER AS FROM MAY 6, 1990

071-928-2020

Not Relevant

BOOK REVIEW

by GRO-D

AIDS: A GUIDE TO CLINICAL COUNSELLING by Riva Miller and Robert Bor (Cambridge Medical Books, Tracey Hall, Cockburn Street, Cambridge CB1 3NB, United Kingdom), 123 pp., pb

HIV/AIDS has revolutionised the comprehensive care approach to haemophilia management. Meeting the psycho-social needs of people affected by HIV is now no longer the sole responsibility of the designated counsellor. All members of the comprehensive care team from doctors to physiotherapists, receptionists to nurses are involved in helping people come to terms with, and live with, their diagnosis.

Learning to counsel people rather than talking to, or advising them can be a difficult process. Health care professionals not equipped with these skills can feel at a loss when all they seem to be able to offer HIV positive persons with haemophilia is bad news. Recognising this, Riva Miller and Robert Bor of the Royal Free Hospital, London, have written *AIDS: A Guide to Clinical Counselling.* The intention of the guide is to help health care professionals develop the expertise needed to assist individuals and their families through the various stages of HIV infection.

Drawing from the Milan Technique, Miller and Bor offer a systemic approach to counselling people with HIV/AIDS. Whilst examining the reciprocity of relationships, they introduce various question types which allows the person being counselled to reach his or her own decisions regarding their health.

The book goes into great detail about sexual transmission and prevention of secondary infections, giving great insight into how to approach difficult subjects such as sex and sexuality. Throughout, Miller and Bor prove the value of counselling for all concerned. They point out how those counselling can avoid the dependency of those being counselled. They also offer tips to reduce staff stress in a clinical setting.

The guide is packed with examples and case histories drawn from the authors' own experience at the Royal Free Hospital, working with all people affected by HIV/AIDS. They take the reader through various counselling sessions pointing out the value of asking certain question types depending upon particular circumstances. The reader is therefore left with both the theory of counselling and examples of how it can be put into practice. These techniques are complemented by a concise explanation of the clinical aspects of AIDS/HIV, written by Dr. Christine Lee, Consultant Haematologist, Royal Free Hospital.

Due to the clarity of its style and the importance of its subject matter, *AIDS: A Guide to Clinical Counselling* will be a timely and invaluable book for all members of the Comprehensive Care Team. Miller and Bor offer the professional who previously was in a dilemma when confronting "dreaded issues", the tools to offer constructive psycho-social support. The book is an invaluable contribution to haemophilia care.

Not Relevant

Not Relevant

Families and Carers affected by HIV and AIDS

Building Support Systems

A One Day Workshop

at

UNIVERSITY OF MANCHESTER

Institute of Science and Technology

on

SATURDAY 28 APRIL 1990

COST £30

Following the success of last year's workshop, The Haemophilia Society, the London Lighthouse and the Family Support Network of the Terrence Higgins Trust are holding another one day workshop to explore the issues for families and carers affected by HIV and AIDS.

The goal of the workshop is to bring together families and carers affected by HIV/AIDS. The aim is to allow people to meet in a relaxed and informal environment to discuss issues of support and mutual interest. We would stress that the purpose of the day is not to expand professional skills but to respond to the needs of those who are directly affected by HIV/AIDS.

We acknowledge that there are many different family structures, and many different sources of care and support, including partners, friends, volunteers and members of extended or non-traditional families.

We will hear some experiences of both self-help and statutory initiatives, look at areas of particular interest, and begin to plan a strategy of local and national co-operation in building an effective support system.

If you or anyone else would be interested in attending please write to Robin Slovoe at The London Lighthouse, 111-117 Lancaster Road, London, W11 1QT. He will send you further details including an application form.

The Macfarlane Trust may be able to cover the cost of the fee but individual applications must be made.

A crèche for children will be available.

Not Relevant

Not Relevant