The Bulletin

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REPORT ON THE NORTHERN GROUP'S WEEKEND CONFERENCE 18th – 20th November, 1983

The Conference was held at the National Coal Board's Training Centre in Newcastle over the weekend of 18th – 20th November 1983. The theme being "Haemophilia Care Today". The aims of the Conference were:–

1. To bring patients and their families up to date on recent advances in care.
2. To give the Haemophilia Society a chance to meet its Northern members, to assess what the members want from the Society and consider what the role of the Society should be, both locally and nationally.
3. Present an opportunity for both patients, their families and staff at the Haemophilia Centre, RVI to consider the treatment provided, especially in connection with the Home Care Programme with the view of improving the service wherever possible.

In total 127 people attended the Conference, 8 Centre Staff, 7 Representatives from other groups, 93 patients and families registered at the Centre.

David Watters and Dr. Korn shared the platform for the opening session. David spoke on "The Role of the Society" and outlined the aims and rules of the Society. He also touched on the goodwill necessary between the central body and local groups. Dr. Korn gave his slide show and talk about running the holiday camp in North Wales.

The highlights of Saturday were lectures by Dr. Peter Jones, Director of the Haemophilia Centre at the Royal Victoria Infirmary, Newcastle, and his colleague Dr. Peter Hamilton, Consultant Haematologist at the same hospital. In the morning Dr. Jones spoke on "Haemophilia Care to Date – Where are we Now." Altogether it was an optimistic and encouraging report.

The mood was continued in the afternoon when Dr. Hamilton spoke of "The Side Effects of Treatment."

Apart from the main lectures there were group sessions on various topics, such as job prospects and education. These were led by interested parties with special knowledge, either haemophiliacs themselves or relatives of haemophiliacs,

and furnished an opportunity not only to meet a wide cross-section of people in similar circumstances, but to air views and concerns in an uninhibited setting.

On the Saturday evening a disco allowed delegates and guests a further opportunity to let their hair down.

Sunday was taken up with more group discussions, and a panel, giving delegates a chance to question staff of the RVI on "Home Therapy and Prophylaxis." Guests on this occasion were Sister Maureen Fearns, Mrs. Brenda Buzzard, Physiotherapist, and Mrs. Jean Lovie, Medical Social Worker. In the afternoon Dr. Jones gave a final lecture on "The Future Care for the Haemophiliac and his Family."

As participants left they were asked to hand in a short questionnaire, stating in what ways the weekend had been a success or failure, what they had learnt, if they would find further meetings helpful.

Conclusions

1. The Conference was a success and interest was expressed in a Day Meeting at a later date.
2. The Conference provided a platform for the Society to explain its role and work. Committee members became real people to those present. Some expressed an interest in working more closely with the Group. Others, because of distance, wish to remain members of the Society but did not envisage being able to attend Society meetings easily.

   The general isolation of families some distance from Treatment Centres was often referred to. With this in mind,

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the Northern Branch has established closer links with members in Cumbria and a Social Worker at Cumberland Infirmary in Carlisle. Society meetings are to be arranged in that area for those on the West Coast next year.

Those at the Conference hope that other areas will hold similar conferences.

3. The RVI Newcastle Centre Staff were overwhelmed by the response for information and opinions about the service provided. Staff have pages of notes on how care can be improved. These suggestions are being taken very seriously. This patient response has been seen as an essential part of a partnership arrangement that must exist between families and those who care for them.
4. There was an awareness by many families for the first time of the position of haemophiliacs in especially the Third World.
5. The weekend was a useful learning experience for all about haemophilia and gave many the opportunity and chance to chat informally with fellow sufferers. The shared organisation of the Conference between Centre and Group was seen as important in drawing in members.
6. Appreciation was expressed to the Society for their funding of the weekend.

George Sanderson

Editor's Note: Congratualtions to George Sanderson and the Northern Group for organising a successful and popular event.

BLOOD PRODUCTS

Two pieces of good news have emerged in recent months about blood products. The first is that of which the Secretary of State for Health and Social Security, the Rt. Hon. Norman Fowler, on 23rd March, laid the foundation at Elstree. This plant will, it is hoped, be able to produce nearly 100 million units of Factor VIII per year and is intended to make the United Kingdom self-sufficient in Factor VIII. The Society has pressed for this for many years, from the time when, with the rapid spread of home treatment in the early 1970's, severe shortages of Factor VIII began to be felt. To meet this shortage, the DHSS permitted the importation of Factor VIII by commercial pharmaceutical companies, and these companies have over recent years supplied around two thirds of Britain's Factor VIII. There were early doubts as to the quality of commercial Factor VIII. In particular, it was feared that commercial material gave a greater risk of hepatitis infection. While this may once have been the case, better donor selection and improved testing have resulted in improved Factor VIII quality. Medical evidence shows that NHS Factor VIII is no better than commercial material as regards hepatitis risk. We have no evidence as yet to whether AIDS may be acquired more readily from commercial Factor VIII than from the NHS product but, of course, if AIDS becomes established in the UK then NHS blood and plasma supplies are just as likely to transmit AIDS as commercial materials. All things considered, haemophiliacs have no reason to be worried about using commercial concentrates. Without commercial materials, neither home treatment nor surgery would have been generally available, and thus the availability of commercial materials has greatly benefitted all haemophiliacs.

The re-development at Elstree will not necessarily mean that commercial Factor VIII will disappear from our lives. It may be that plasma supplies may not be sufficient to allow the plant to operate at full capacity, and it seems likely that more than 100 million units of Factor VIII will be needed before long. Thus there may be a role for commercial Factor VIII for some time to come yet.

The second piece of good news is the successful production of Factor VIII by "genetic engineering" techniques, which may open the way to Factor VIII being produced in much larger quantities (and perhaps cheaper). This achievement will be reported more fully elsewhere in the Bulletin, but it is worthy of note that the work has involved collaboration between workers at the Royal Free Hospital in London and two commercial organisations (Speywood Laboratories of Wrexham and Genentech of California). Presumably, therefore, synthetic Factor VIII will be manufactured and marketed on a commercial basis by these companies like any other drug.

K. E. Milne

HOLIDAYS HOLIDAYS HOLIDAYS

Each year the office in Trinity Street is besieged with "last minute" enquiries about Holiday Insurance. Members should attempt to arrange their holiday insurance as far in advance as possible, in event of there being any problems. We have all the information available in the office and remember ***the insurance policy which has been negotiated on our behalf is GUARANTEED to cover people with haemophilia. This MAY NOT always be the case with package deal insurance cover. You should check very carefully – although we would advise that the best way to make sure you are covered is to take out the Society's separate policy!***

AN ALTERNATIVE ROAD TO FREEDOM

Lawrence Lever examines the virtues of a new scheme for disabled drivers

In 1981, the Year of the Disabled, John Harris called a seminar for organisations and individuals representing disabled people. As a result of information gleaned at the seminar he subsequently pioneered – through Consumer Insurance Services his specialist insurance brokerage – a combined form of vehicle insurance and breakdown/recovery service which proved very popular with disabled motorists.

He also came away from the seminar with reams of notes on the general problems experienced by disabled motorists. These notes, together with two and a half years of research and consultations with disabled organisations, provided the springboard for AID – Assistance and Independence for Disabled People -- a new scheme launched this week to help disabled people purchase cars.

Mr. Harris describes AID as "an alternative form of Mobility." In effect it is an alternative to Motability, the Government-supported charity set up in 1977 to convert the Mobility Allowance, paid to disabled people who are unable or virtually unable to walk, into cars.

Altogether there are some 320,000 disabled people in Britain receiving the non-means tested Mobility Allowance of £19 a week. Added to this are a further 8,590 people who receive Mobility Supplement, a similar benefit for war pensioners, which is fixed at £12.15 a week.

Broadly speaking Motability provides cars, on a three year leasing or 4½ year hire purchase contract, in return for payment of the disabled person's Mobility Allowance (or Supplement) for the length of the contract. New and secondhand cars are available for hire purchase, whilst the leasing contract is restricted to new cars.

Some 42 per cent of the cars Motability provides are leased. The major drawback here is the fact that at the end of the three year period of the lease the car reverts to Motability, thus leaving the disabled driver without a car for the money he or she has been paying, over the period of the lease.

It was partly because of this problem that Motability introduced a hire purchase form of providing cars, and this facility is proving more popular with its clients.

Like Motability, the AID Scheme will provide both new and secondhand cars on a hire purchase basis. There are, however, quite a few differences between the two schemes that are worth noting.

AID will provide 50 different models for hire purchase on a no-deposit basis.

The scheme, unlike that provided by Motability, is open to any disabled person, not just those receiving Mobility Allowance or Supplement, including those who are deaf.

Obviously the availability or otherwise of the Allowance or Supplement will be a relevant factor in assessing the disabled person's ability to meet the repayment schecule. But a general view of his or her resources will be adopted taking into account other sources of income, i.e. from a part-time or full-time job. "There are no hard and fast rules," stresses Mr. Harris.

If you take one of the 50 models (others will be available, depending on individual's needs and tastes) what do you get for your money?

Built into the cost is life assurance cover for the disabled driver which lasts for the first two years of the hire purchase term and is provided without any medical examination.

Also included throughout the five year term are fully comprehensive insurance; a 24 hour breakdown or accident recovery

The Lord Mayor of Newcastle upon Tyne, Councillor Arthur Stabler and the Lady Mayoress held a Coffee Morning at the Mansion House in aid of the Northern Group of the Haemophilia Society. A silver salver of money was handed over by the Lord Mayor and was received on behalf of the Society by Dr. Peter Jones, Director of the Haemophilia Centre at Newcastle's Royal Victoria Infirmary. Photo – left to right: Lord Mayor; Lady Mayoress; Mrs. Lorna Reynolds, Chairman Haemophilia Society Northern Branch; Dr. Peter Jones, Director, Haemophilia Centre, Royal Victoria Infirmary.

service; and legal expenses insurance for any motoring prosecutions, but limited to £5,000 of expenses per incident. AID also handles any insurance claim on your behalf free of charge, and provides a free legal advice service available for any problems, motoring or otherwise.

The hallmarks of the scheme appear to be its flexibility – drivers can sell or switch cars mid-contract – and the fact that it provides a fairly complete service, negotiating with the relevant bodies on the disabled person's behalf.

AID is financed through a subsidiary of the Greyhound Corporation (which runs the Greyhound bus system in America among other things) and has a panel of disabled people who are specialists in the problems of the disabled motorist.

Although AID appears to be the more flexible scheme, this does not mean that you should automatically discard Motability from your plans if you are thinking of buying a car.

Motability does have charitable funds available to help people who do not have the resources to pay for adaptations or the initial deposit on a car. So far it has paid more than £600,000 in grants for this purpose, and last year helped 309 disabled drivers to the tune of £101,000.

Generally you should always see what Motability and AID have to offer before committing yourself to one or either of them. Clearly a comparison between the respective costs of obtaining a car will be a very relevant factor in your decision.

Do not assume that because AID cars are offered on a no deposit basis they will necessarily be cheaper. Similarly, although Motability's repayments are based on an interest rate of 15.07 per cent as opposed to one of 19.5 per cent of AID, this does not mean that AID is more expensive when you take all the costs into account.

If you have to borrow for the deposit or the subsequent instalments, then you should approach your bank manager. The DHSS now offer you the facility of having the Mobility Allowance paid directly into your bank account and this may help sway your manager to provide the finance that you need.

Motability, Boundary House, 91-93 Charterhouse St., London EC1M 6BT. Tel. 01-253 1211.

AID Centre, 182 Brighton Road, Coulsdon, Surrey CR3 2NF. Tel. 01-645 9014.

Mobility Information Service, Copthorne Community Hall, Shelton Road, Shrewsbury. Tel. 0743 68383

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HANDLING THE MEDIA

Not always, but certainly quite often, reporters are asked to report on a subject about which they have no knowledge whatsoever. Instant experts, if you like.

Invariably, the first thing they do is ask their office library to produce all the previous material on the subject from their own – and other papers. The cuttings are produced and all the old errors and clinches will be read over. For example, the reporter reading up on haemophilia will be reminded that it's a blood disorder "whose victims can bleed to death from the slightest scratch". It's a piece of regularly repeated nonsense that is still too eye-catching to resist. And, after all, there it is in black and white.

Armed with such basic appreciation of the subject, the next thing our reporter will do is track down a source of information who, he hopes, can bring him up to date on the particular enquiry he's making and, above all, provide him with some "good quotes".

You may be that source of information.

Resourcefulness and persistence are the reporter's stock in trade and perhaps through his local hospital, he will find the Secretary or Chairman of the local Group of the Haemophilia Society. Don't be rushed into responding, because what you say is being taken down and, as the law puts it, may be used in evidence – or headlines – against you!

Don't be tempted to give opinions or facts if you are not 100 per cent sure of the details. That may sound childishly obvious, but it is staggering how often it happens. To be fair, the reporter himself will be happier to be referred to someone with firm professional knowledge if you point out that you are not the person "in the know".

Before getting into conversation – either on the phone or the doorstep – demand to know the reporter's name (he'll want yours) and who he is working for. Give him the name and phone number of someone more competent than yourself or, at worst, ask him to call or ring back after you have had time to consult someone yourself to get more information.

The story he's after may well cause distress if not handled carefully – something our reporter may have completely, and genuinely, overlooked. If you have all the details make sure he appreciates and understands the difficulties. If his questions are clearly aimed at criticising you or the Society a "no comment" may well be made to look damning in the final story.

After all, don't be drawn into agreeing with comments or remarks he may make in the most off-hand way. An old reporters' trick as he's about to ring off or walk away, is to say: "I'm sorry you can't help, but it's all pretty disgusting the way the thing is being handled isn't it?" You may be tempted to murmur: "Frankly, I tend to agree" and tomorrow find a headline saying 'Local Society Officer attacks the disgusting way issue is being handled'.

Groups should appoint a press officer if they can. He/she could then be armed with the phone numbers of experts who can advise on tricky situations. If the issue is clearly a national one, refer up as high as possible. The Society's Officers are concerned with all current questions and the Co-ordinator, David Watters, is the vital contact.

And finally; my indictment of reporters – like all generalisations – does not always hold true. Medical correspondents, particularly on the quality papers and broadcasting organisations, usually know their subject and are anxious to improve their knowledge. They are also anxious to secure and keep good contacts. That sort of journalist may be as much value to you as he hopes you will be to him. He may even be persuaded to give away trade secrets at a Society Seminar . . **John Spicer**

Part of the 'Handling the Media' session at the 1984 Group Seminar.

WFH TEAM VISIT TO ROHTAK AND DELHI, INDIA

November 25 to 27, 1983

In November, the Indian Society of Blood Transfusion and Immuno-haematology met in Rohtak, Haryana. This was an immensely important occasion for people with haemophilia in India because, although these blood bankers meet regularly to discuss their national blood policy and technical subjects associated with their professional work, this was the first time that such prominence had been given to haemophilia.

One whole morning session was allocated to a Symposium at which the speakers and their subjects were:

Professor P. M. Mannucci, Italy. Chairman, International Haemophilia Training Centre Committee and Vice-President of the World Federation of Hemophilia
Simple approaches to the diagnosis of hemophilia and allied disorders
Blood components in the management of hemophilia

Dr. A. Ahlberg, Sweden
The role of the Orthopaedic Surgeon

Dr. Bruce Evans, United States of America
Dental care

The Reverend Alan Tanner, United Kingdom. Chairman of the World Federation of Hemophilia
The role of the National Hemophilia Societies and the World Federation of Hemophilia.

Their introduction to the subject gave rise to important discussions, not only at the Symposium itself but at the informal occasions which were associated with the Conference. It was evident that there is a great deal of concern among doctors and scientists in India that the supply of blood products should be increased substantially and the facilities for the treatment of haemophilia improved as soon as possible.

The team, led by Professor Mannucci, was welcomed most warmly at an impressive inaugural session in a large Open Air Theatre erected in the grounds of the hospital for the occasion. The theatre was packed to overflowing with members of the Conference, students from the Medical College, nurses from the hospital and others who had come to hear the Chief Minister and leaders of the Medical Profession give the opening addresses at this memorable event. The programme indicates clearly the strong support given by all concerned with health care in general and haemophilia in particular.

Chief Guest: Ch Bhajan Lal, Chief Minister Haryana

Dr. Chandra Prakash
Welcome address by the Chairman, the Organising Committee

Shri M. Kuttapan
Address by Health Secretary, Haryana

Mrs. Saroop Krishen
Address by Secretary-General, ISBTI

Ch. Hardwarl Lal
Release of Souvenir and ISBTI Directory by the Vice-Chancellor, M.D. University, Rohtak

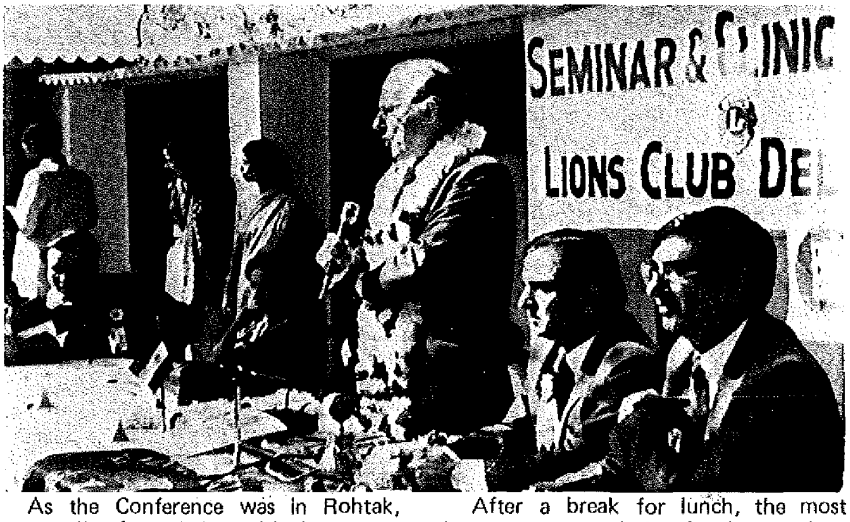
Col. A. K. Dutta
Presidential address by ISBTI President

Smt. Prasanni Devi
Inauguration of Exhibition by Health Minister, Haryana

Prof. P. M. Mannucci
Greetings from the World Federation of Hemophilia

Ch. Bhajan Lal
Inaugural address by Chief Minister, Haryana

Dr. M. S. Yadav
Vote of thanks by Organising Secretary



As the Conference was in Rohtak, forty miles from Delhi, with the accommodation for members of the team being provided in the Haryana Bahana, a Government hospitality residence in New Delhi, the team was involved in travelling by car for two hours at the beginning and end of each day. This might be thought a rather inconvenient arrangement for the visitors but it proved to be a distinct advantage for, by returning to New Delhi for the evenings, they were privileged to share the delights of Indian hospitality and also had a unique opportunity to meet in their homes key people involved in the development of national facilities for haemophilia and those who are taking an initiative in establishing a national haemophilia society.

The team's visit had as its climax a special day for a seminar and clinic at the Lions Hospital and Research Centre in the Village Khizrabad in New Delhi.

Wide publicity had been given to the Seminar, with letters sent to all known peole with haemophilia throughout India as well as to doctors and others who might be able to disseminate information about this unique opportunity to meet specialists from other countries. The splendid arrangements were made by the Lions Club Delhi Capital and the local doctors concerned with haemophilia.

For this very special event, great efforts had been made to prepare the Lions Hospital for the crowd of people who were to attend, so the whole occasion had an atmosphere of brightness and expectation. The Seminar began with official welcomes extended to the team and the presentation of colourful garlands of flowers in the traditional Indian fashion. Officers of the Lions Club and others spoke of their hopes for the future care of people with haemophilia in India, after which members of the visiting team gave brief introductions to their own special subjects.

After a break for lunch, the most important part of the day began. At a Clinic to which all people with haemophilia had been invited, members of the team saw each patient in turn and made an assessment about his condition and a programme for future care.

This was a most impressive and moving occasion as some of the patients had travelled very considerable distances to be present. (I met one family who had travelled by train for seventy two hours from South India) and all were eager to have information about their condition and advice about the ways in which their problems might be alleviated.

A very special mention must be made of the way in which the doctors in the team gave their undivided, sustained attention to this Clinic, seeing over seventy five patients in the course of the afternoon, in conditions which were rather different from those to which they are accustomed in their own consulting rooms and hospitals, and with very little break between the consultations.

At the end of the day, the people with haemophilia and their families came together to consider how they might form a national society to improve the facilities for treatment, increase the supply of blood products and support each other as a fellowship.

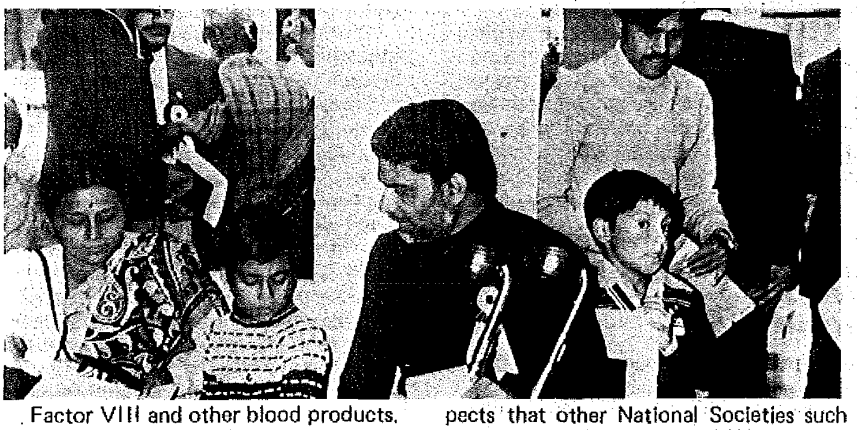
The Reverand Alan Tanner, Chairman of the World Federation, opened this

RE-INDIA

meeting by reminding members that the World Federation of Hemophilia was that very year celebrating the twentieth anniversary since its formation. In 1963 Frank Schnabel had called together representatives from six national societies and the organisation had now grown to the point where sixty national societies were members.

He went on to give a brief outline of the benefits which would follow from the formation of a National Society and summarised the immediate objectives for which the members might aim:

1. To increase substantially the supply of good quality cryoprecipitate and other blood products.
2. To encourage the development of the voluntary blood donors programme.
3. To make representations to the appropriate government authorities for financial support for the provision of Factor VIII and other blood products.
4. To establish Haemophilia Centres throughout India to provide comprehensive care.
5. To provide support and advice for members and to improve the quality of life of people with haemophilia.
6. To identify people with haemophilia who are not yet in touch with hospitals or doctors.



Mr. Ashok Verma who, with Mr. George Tharakan, had played a large part in the preparations for the Seminar, reported on conversations which had already taken place in other parts of India regarding the formation of a National Society.

In the lively discussion which followed it became clear that the most effective way forward would be in developing activities in the several areas of India where Chapters of a potential society were already active. In view of the great distances involved in travelling, it was agreed that growth in local activities would be the most promising development and it was reported that such Chapters were already functioning in

Kerala
West Bengal and
Maharashtra.

It was formally agreed that:

1. A national society with the title "Haemophilia Federation of India" should be formed.
2. In the first instance, efforts should be concentrated on the establishment of a Haemophilia Centre based on the Lions Hospital in New Delhi where the meeting had taken place.
   This would be used as a pilot scheme to be followed by the development of Centres in other places where the Chapters were active and doctors specialising in haemophilia were available.

The Reverend Alan Tanner as Chairman welcomed these decisions and undertook to advise the officers of the newly formed Haemophilia Federation of India about the form of Constitution to be adopted and the way to apply for membership of the World Federation of Hemophilia. He also reported that there were good prospects that other National Societies such as the United Kingdom, would be prepared to consider helping in the development of the new Federation's work, once definite plans were drawn up, and he offered to make approaches for support for, for instance, the designation of the Haemophilia Centre in New Delhi.

Copies of important documents provided by the World Federation were left with the officers of the new organisation. Among these papers were:

The Administrative Handbook – giving guidelines for the activities of National Societies

The Passport for Travellers – giving details of treatment in countries throughout the world

The History of Haemophilia.

Conclusion

There is obviously much to be done in India.

In this splendid, vibrant country with a population of over 540 million with 80% living in the villages, the number of people with haemophilia identified so far is measured in hundreds rather than the tens of thousands we would expect. Supplies of concentrates are minimal and both cryo-precipitate and plasma are scarce.

The very positive signs are in the fact that there is an increasing awareness of the needs to be met and a desire on the part of Haematologists and Blood Bankers to take positive steps to improve this situation.

We are immensely grateful to Dr. Jolly, whom we have met previously at World Congresses, and other officers of the ISBTI, for giving such prominence to Haemophilia in their programme on this particular occasion.

The other major points for optimism are in the evident, strong practical support being given by the Lions Club to the whole endeavour. The Lions Club is a powerful organisation in India, and in Delhi in particular, and we are singularly fortunate in having this personal interest expressed in such positive terms by their senior officers. Equally impressive is the active participation in the new programme by a number of young men who, having haemophilia themselves, are strongly motivated in their zeal to develop the Indian Federation. So the future in India is full of hope.

At the Seminar, as we looked to the future on that memorable day, we took as our theme:

"Today is the first day of the rest of my life."

November 27, 1983, marked a very significant day in the whole development of haemophilia care in India and will prove to be a turning point in the lives of many of our members there.

I finish on a personal note.

First, we were privileged to be involved in such a satisfying, creative event. It was an outstanding opportunity for developing the potential present in the Haemophilia Federation of India and I have every hope that we shall hear reports of major progress throughout the country.

Secondly, I must pay tribute to the other members of the visiting team. As the lay member of the group, I can say that it was a superbly balanced team led in his inimitable way by Professor Mannucci who, with the other members, Dr. Ahlberg and Dr. Bruce Evans, devoted themselves with unflagging zeal to the strenuous activities of the programme and the particular demands made upon them at the Clinic.

Visitors to India invariably carry away lasting impressions of the wonder, variety and rich culture of the country and her people.

Our visit was no exception and we know that we now have good friends whom we welcome into the fellowship of the World Federation of Hemophilia.

Alan Tanner

The Chairman of the World Federation of Hemophilia expresses his gratitude to CUTTER INTERNATIONAL whose generosity made his journey to India possible.

WORLDWIDE

W.F.H. News

WHERE IN THE WORLD IS YOUR PEN PAL?

Young people with haemophilia in the six to twelve years age group who are seeking pen pals are invited to write to the Co-ordinator. The World Federation of Hemophilia in Montreal is co-ordinating an International Pen Pal system and names will be forwarded from London to Montreal in due course. Letters should mention subjects which the person is interested in, and the Country in which they would like to have a pen pal.

HAEMOPHILIACS IN EASTERN INDIA

To apprise anybody of the plight of haemophiliacs of Eastern India or even India as a whole, is a difficult task, likely to be inaccurate one, mainly because of non-availability of statistics. It is so because, up till now there has not been any National/State level programme or so to say initiative through articles in newspapers/magazines that would ease the job. So I shall try to highlight on the mode of change that has occurred/likely to occur as we hope to be fair enough, with the formation of Haemophilia Society, Calcutta Chapter in September, 1983.

With a tips about Eastern India, it consists of ten states namely Bihar, West Bengal, Assam, Orissa, Tripura, Meghalaya, Mizoram, Manipur, Nagaland and Arunachal Pradesh. Calcutta is the capital of West Bengal as well as the largest city in this part of the country.

What we find most when dealing with this dreadful disease is lack of general awareness, among the patients, among the general public including the near one of the patients and to some extent, I should say, among the doctors too. To cite an example, one severe haemophiliac aged 32 years has been confined to bed since his 12th year because of frequent spontaneous haemorrhages into almost all of his joints. All those joints are now badly deformed. One of the leading haematologists of Calcutta had been looking after him and so far he was being given only fresh blood transfusion despite the fact that cryoprecipitate and plasma (fresh and frozen) were available for quite some time in Calcutta itself. And the patient and his parents regarded the haematologist next to God. They used to believe that the patient is living still today because of that haematologist's care only. Neither the patient, nor his parents had any knowledge about the cause, nature or management of haemophilia until the members of our society made them understand all. Here comes the objective of our society. Its prime objective is to educate all concerned about the disease especially to remove the misconception about the disease from the patient's as well as their well wisher's mind to make them aware about the channels/methods available to fight the disease. The President of our Society Dr. D. K. Bhattacharya, himself a haematologist has been preparing 'cryo' and fresh frozen plasma in his Research centre on Haematology. Although our intention is to supply 'cryo' and 'plasma' to all haemophiliacs free of cost this is likely to be defeated for the simple financial reason. To do this for 100/200 patients is one thing and doing this for thousands of persons quite another. With most conservative guess there will be at least 10,000 haemophiliacs in Eastern India and our aim is to reach every one. Side by side, we shall try for better diagnostic facilities, that are available only in Calcutta to spread to other parts of Eastern India. In Calcutta even, the centres where a haemophiliac's deficient factor level can be measured accurately are not well up to the need. Still I shall reiterate that the condition of haemophiliacs here, as it stands today, is better than it was even a year ago.

Before I close, a few words about the Society. The Calcutta Chapter of Haemophilia Society was formed with the inspiration of Mrs. M. I. Britten, London Secretary WFH, Mr. Matthew Maynard, WHY President, and Mr. George Tharakan of course who had started Haemophilia movement in India.

We have also been successful in forming the Haemophilia Federation of India on 26th November, 1983. Rev. Alan Tanner, Chairman of British Haemophilia Society, presented our haemophiliacs with the slogan "27th November, 1983 is the first day for the rest of our life."

Tarak Banerjee

HAEMOPHILIA – A PERSONAL ACCOUNT

By Steve Elsworth

I discovered I was a haemophiliac when I was 21 years old. I know this is a dramatic statement to make, but it was not like that at the time – it just happened, like spraining an ankle or having flu. One morning, I noticed that my urine was the colour of port wine, so I went to my GP and was whisked into hospital. A week later, after various tests, I emerged as a 'card-carrying bleeder'.

As far as I was concerned, that should have been the end of the matter. Unfortunately, it was not. Haemophilia, like leprosy or rabies, is one of those strange medical conditions which has entered the public consciousness without people being fully aware of the details of the disease. If you ask someone to write down what haemophilia means, he or she will probably write 'Possibility of bleeding to death . . . sheltered life-style . . . needs to take no risks . . . should be protected from bumps and bangs.' This perception affects the way that people react to haemophiliacs: it can stop them getting jobs, make it difficult for them to buy insurance, and even affect their social relationships. The perception is also completely out-of-date. It may have been valid 50 or even 30 years ago, but medical advances since the 1960s have changed the face of haemophilia. It is no longer a condition which excludes a person from a normal life-style.

Clotting deficiencies

The word 'haemophilia' is used to describe a group of inherited conditions in which there is a deficiency in a blood clotting factor. True haemophilia (haemophilia A) is the most common, and is characterised by a lack of factor VIII: Christmas Disease (haemophilia B) is characterised by a deficiency in factor IX. Both A and B are genetic disorders which can be passed on by mothers but, with rare exceptions, they affect males only. Von Willebrand's disease is the third member of the haemophilic group; it involves a combination of factor VIII deficiency and abnormal platelet function, and affects either sex.

There are nearly 6000 haemophiliacs in the UK, approximately 4600 with haemophilia A, 800 with haemophilia B, and the rest have von Willebrand's disease (the von Willebrand's register is still being compiled). As in diabetes, patients are encouraged to diagnose and treat themselves. About 25% of Britain's haemophiliacs have been trained in the skills of home treatment; when they feel a bleed starting, they can inject themselves intravenously with freeze-dried factor VIII or factor IX concentrate.

It is the development of these concentrates which has changed the treatment of haemophilia and made such a difference to haemophiliacs' standard of living. Previously, a bleed into a joint necessitated a long period of bed-rest (often with the patient in great pain) until the bleeding stopped. The discomfort of haemophilia is not that you cut yourself and cannot stop the bleeding but that when you whack an elbow or a knee against something hard, you start to bleed internally into the joint. This can also occasionally occur spontaneously. The joint swells up and stiffens, becomes very painful to touch, and is almost impossible to move. To avoid such episodes haemophiliacs used to wear padding around the legs and arms, and anxious parents would keep a careful watch on affected children and try to ensure that they did nothing which would place them in physical danger. Nowadays, these precautions are unnecessary. If a bleed is treated early enough, clotting occurs quite quickly, and minimal damage and discomfort occur. The onus is on self-diagnosis rather than self-protection.

Getting used to the idea

Fortunately, my haemophilia was diagnosed at a relatively late stage. Looking back to my childhood, I can now remember nosebleeds that lasted for hours, large-scale haemorrhaging after I had my tonsils out, and the occasional bruised hip after playing rugby. However, the condition was not diagnosed, so I was able to accumulate all the normal physical experiences without anyone telling me what I should or should not do; this was to prove very useful later on.

After my haemophilia was diagnosed, I went back to start my third year at university, and found that I had become a different sort of animal. Well-meaning friends were over-protective, acquaintances would come out with the same old

jokes, and people in authority (certain university lecturers) tried to stop me from doing things which I had been doing quite happily for years. It took some hard talking before I could carry on my job of 2 years' standing as a bouncer at the university discos. I was told that I should behave more responsibly, drink less, and be much more careful with myself. All this came to a head when I went to see a GP (not my own) with a pain in the chest that I had collected from playing football. He was horrified at the very idea of a haemophiliac taking part in such an activity: "What do you mean, taking chances like this?" he demanded, genuinely shocked. I looked at him and realised that we just could not communicate about my condition. As far as I was concerned, I had been playing football for the past 16 years, and I was not going to stop just because I had picked up a new medical label. On the other hand, I was rather shaken by his outrage. I decided to see if I could take a year out of college to think about it. Normally, this was a very difficult procedure; but the word 'haemophilia' allowed me to get a year's absence in the space of 3 days.

Haemophilia centres

It did not take long to get accustomed to the idea that I had haemophilia, but this was only after I learned how to use the haemophilia centres. These centres are attached to designated hospitals around the country and they provide treatment, advice, reassurance, and most importantly, an atmosphere in which haemophilia is discussed practically, with no hysterical overtones. I took my football problem to my local centre, and received the reply: "Exercise is as important for haemophiliacs as for anyone else. If you are happy playing football, fine. If, however, you are continually getting bleeds from the game, then maybe it is time to think about stopping."

The centres take great pains to ensure that haemophiliacs understand their condition, and in the case of children, that their parents are fully aware of what is going on. If a bleed occurs, it is essential to treat it as quickly as possible, either by injection of concentrate or of some other blood product. Children are trained to be self-aware, to involve their parents if they have small accidents or feel a bleed coming on. Parents are encouraged not to be over-protective, but to take reasonable precautions. The difficulty with haemophilia is the balance between looking after yourself and leading a full, uninhibited life – the people who work in the centres are extremely adept in promoting both sides of this equation.

Home treatment

There are various degrees of haemophilia. People who have less than 1% of factor VIII or IX are classified as severe; 1–5% moderate; 6–24% mild. I have 18% factor IX, so it was explained to me in the Centre that I should not expect to need treatment all that often. In fact, I could go for some years without seeing the wrong end of the needle. However, there was a period some years ago when I seemed to be falling over anything and everything, and consequently had a few bleeds; it was at that time that I found out how to treat myself at home.

Home treatment involves keeping a supply of freeze-dried concentrate in the fridge, and injecting yourself with it when you feel a bleed starting. There is a definite 'aura' to most bleeds, a warm tingling feeling that is very recognisable. The factor VIII or factor IX dose lasts only a few hours, but if treatment is given promptly, one injection is sufficient to stop most bleeding episodes.

About 25% of Britain's haemophiliacs now treat themselves at home, and this has profound implications for their mobility, standard of living, and general health. I do not have severe haemophilia, and cannot therefore speak for those who do. In my experience, however, the medical aspects of haemophilia are being coped with adequately (short of finding a total cure).

Room for improvement lies in the social aspects of the condition. I am quite reticent about my haemophilia; I make a point of not telling people about it unless there is a special need for this information. This is because, socially, I quickly got bored by people's sensational responses to the news that I am a haemophiliac and, professionally, it has occasionally prevented me from getting jobs. For example, I worked for a year as a scaffolder on a building site and I told the foreman about my condition 4 months after I had been working there (by which time I had had plenty of opportunity to establish myself); as the foreman told me then, if I had mentioned my haemophilia to him at my interview I would not have got through the site gates.

In conversation with the severe haemophiliacs that I have met, I have found that their philosophy and mine are markedly similar. OK, they say, so my blood does not clot properly, and occasionally I have to help it along, but that does not mean I am a freak, or that I need extra special protection and cannot lead a normal life. This is the practical viewpoint that is engendered in the haemophilia centres and encouraged by the Haemophilia Society and, although in my experience this philosophy is not shared by all members of the medical profession, I feel very strongly that it should be. Soon, given time, it will.

Useful address

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Lyn and Terry Fitton's first venture of fund raising for the group was an outstanding success. After many weeks of preparation they held their jumble sale and raised a remarkable £380 – this must be a record! Well done, and thank you Lyn and Terry!
The photograph shows Lyn Fitton with Joseph who has haemophilia, along with his sister Lucie and Sister Marian Gregory of Ladywood Children's Hospital, who receives the cheque from Lyn.

BOXFILE

Revised Benefit Rates

The new figures for pensions and other Social Security Benefits have been announced by Norman Fowler. For the second year in succession, the increase is based on how much inflation rose in the twelve months up to May.

However, at the same time, the Government have decided to change the timing of some payments which will save the Government millions of pounds since the higher rates will be paid from November 26th, which is 53 weeks after the last increase. We reproduce the figures here for the interest of members.

Mobility Allowance and Attendance Allowance

Having successfully fought a large number of applications and appeals for Mobility Allowance and Attendance Allowance, the Co-ordinator is now compiling a detailed report on the subject. It is fairly obvious that members of the Society have benefitted by something in the region of £150,000 per year in income through those allowances but a large number of people have not let us know the result of their application and we would also be interested to know how many people applied as the result of various pieces appearing in the Bulletin and whose applications have been successful, without any help from the Society.

We would stress again that we are prepared to look at any and every application from a person with haemophilia who feels that they have a reasonable application to make.

Over the next few months consideration will be given to the pressures that can be brought to bear on the relevant authorities as statistical pictures begin to emerge.

Points of View

Dear Sir,

In a recent report of the Group Seminar Proceedings, the group considering "genetic counselling and its benefits" expressed the view that "genetic counselling should not be carried out by the medical profession, because the medical profession is too biased towards prevention of genetic disorders." Furthermore, the view of the group was that "telling people probabilities with which their children might be affected is only a small part of counselling."

I would like to disagree with the contention that genetic counselling, as practised by the medical profession, is biased towards prevention and the communication of risks alone. There is a steadily growing number of doctors, working in clinical genetics and haemophilia centres, who have been trained in medicine, genetics and genetic counselling. A recent Working Party report of the Clinical Genetics Society on the role and training of clinical geneticists[1] emphasises that "Genetic counselling involves the collection and communication of information relevant to the occurrence of genetic disorders in families, thus providing and interpreting medical information based on an expanding knowledge of human genetics. The aim is to convey understanding of genetic problems and to reduce stress, anxiety and fear of the unknown. Accurate risk estimation and counselling enables prospective parents to make informed decisions about child bearing."

It should be noted that the main theme is to give individuals as much information as possible about genetic disorders and to allow them to make their own decisions about child bearing. The report goes on to say that:— "The clinical geneticist is always conscious that an accurate diagnosis and estimation of risk of recurrence in a relative is the minimum, not the complete requirement. But it cannot be too strongly emphasised that sympathy and good intentions are no substitute for factual accuracy. Genetic counselling is potentially harmful if it is not backed by skilled clinical and laboratory diagnosis, accurate genetic interpretations and precise risk estimation. The importance of accurate content must be guaranteed, while emphasising that genetic counselling is ineffectual without the skills of communication and the emphatic interaction with the client which makes each counselling session unique and demanding. The counsellor uses skills in listening so that the patient is encouraged to communicate freely, to verbalise fears and expose misconceptions, to understand the medical genetic content and ultimately to make appropriate decisions."

It is time to get away from the time-honoured rivalry between medical and non-medical professionals. No one is uniquely unsuitable to give genetic counselling. It is far more important to stress that genetic counselling involves a difficult combination of sound genetic and medical knowledge, together with communication skills and that those who undertake this responsibility, whether medical or non-medical, should have received adequate theoretical and practical training.

Robin M. Winter, MB BSc MRCP
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Ref. 1.: Harris et al (1983) Clinical Genetics Society: Report of the Working Party on the Role and Training of Clinical Geneticists.

BOYS AND THEIR EDUCATION

In collaboration with the Social Work Department of the Royal Free Hospital, we are trying to assess educational opportunities for boys with haemophilia. If you are extremely happy with the way your son is treated at school — then let us know! Equally if you feel things are not as they should be, then let us know that as well. In this way we will be able to feed new information into publications, for both parents and teachers. We would welcome your replies to the following simple questionnaire as soon as possible. You need not identify yourself, although this would of course help when checking any replies which raise doubts.

Completed questionnaires should be returned to the Co-ordinator at 16 Trinity Street.

YOUR NAME (Optional)

_____

1. **LUNCHTIME ARRANGEMENTS**
   Does your child take lunch in the common dining room?
   YES/NO
   If NO what alternative arrangements are made?

2. **BREAK OR PLAYTIME ARRANGEMENTS**
   Does your child go with the other children to the playground?
   YES/NO
   If NO what alternative arrangements are made?

3. **SPORT**
   Does your child take part in sports such as
   Football
   Physical Exercise
   Swimming
   Athletics
   If YES which sports and what additional ones?

   If NO what alternative arrangements are made for him during sports time?

4. **SCHOOL ABSENCES**
   If your child is absent from school — how does he catch up with the work?
   (a) Read it up by himself
   (b) Ask teachers for help
   (c) Expects to catch up at the next lesson
   (d) Other method.