GENERAL SECRETARY'S REPORT

Confidential

1 May 1992

General Secretarys Report May 1992

This is my first formal report to the Executive Committee for some time and, as such, it may be lengthy and cover subjects dealt with elsewhere in the Agenda.

1 STRATEGIC PLANNING The timetable for the Strategic Plan has been very tight and the Executive Committee should note the exceptional work put into the Plan by Graham Barker who has worked through weekends and the Christmas Holiday to meet target dates. The process has – just –met its deadlines and soon after 6 May members of the Executive Committee will receive a copy of the Plan and the Consultation papers. It will be important to secure a good response through the consultation both from the Executive Committee and from key people in the world of haemophilia –Council members, MAP, etc. The afternoon session on 16 May will be devoted to the Plan.

2 **PEOPLE** GRO-A – as you will know from my memo and from the national media – has undergone knee replacement at the Royal Free Hospital with the benefit of 'cover' using recombinant factor VIII. Although I have not spoken personally to GRO-A for some weeks I know from reports – and pictures – that he is in good shape!

3 **MEDICAL ADVISORY PANEL:** Attached to this report [Annex 1] is a copy of our report to the November meeting of Council regarding the Medical Advisory Panel. For a number of reasons I feel that we should review the personnel involved – in particular I refer to our proposal that Dr C A Lee should represent hepatitis. It should clearly be Professor Preston in view of his status within the CDO and his very great helpfulness in relation to hepatitis generally. Apart from that the Executive Committee had in mind appointing:

Dr Elizabeth Mayne – Chair
Dr Christopher Ludlam – Scotland/Northern Ireland and HIV treatments
Dr Geoffrey Savidge – Product Purity
Dr Charles Hay – NHS Reforms and prophylaxis
Professor Arthur Bloom – Scientist and vWd
Professor Eric Preston – Hepatitis

In addition Dr Peter Jones has made a special plea for inclusion and I have sympathy with that request: he is useful and skilled communicator and an experienced paediatrician.

Dr Ted Tuddenham's expertise on genetics should, perhaps, be included as and when we require it.

Those proposals do not substantially reduce the size of the panel and the Committee may consider omitting the name of Dr Charles Hay. Although he is always more than ready to be of help he is not an existing member.

It is important that definite proposals are drawn up for presentation at the AGM.

The MAP met at 123 Westminster Bridge Road on Thursday 9 April. Members of the Executive Committee have already received a copy of the Minute of that meeting.

4 **WORK WITH LOCAL GROUPS** Earlier in the year I held three meetings in Scotland for local Group Committees and Group Officers. I was assisted by Andy Cowe and Norma Guy. The meetings were successful in that they were not complacent and brought up many home truths – perhaps the greatest being that local Groups simply do not know, and indeed make very little effort to know, their local people. Without that very preliminary step local groups cannot know the local problems or be able to identify the local issues at stake. "We've held five BBQs and no one comes"; "We write and ask everyone to meetings but they don't come" are two simple examples of the cries one hears. If we are to continue with Groups – IF – then they need to have their tasks defined so that they will successfully identify needs, problems and issues emanating from those needs and problems.

This was perhaps borne out most clearly with my next round of meetings in the Northern swathe of England and Wales. My 'first round' meetings are for all Committee members and they were notified in late 1991. I was shocked to find that attendance was to be as follows:–

Northern Group: 5
North West: 10
Merseyside: 1
North East: 0
North Wales: 1

Well done Northern and NW – but otherwise what a statement of lack of commitment!

In the 'other half' of that weekend I was due to meet the following numbers from the following Groups:–

Sheffield: Maybe 3 – 1 definite
Nottingham: 0
Leicester:1
Lincoln: 4
Derby: 3

Again, well done those who scored more than one!

In the event and after consultation with Ken Milne, GRO-D and the Chairman I cancelled those meetings at very short notice since I could see little point in spending my time and Society resources on events which were clearly not wanted. The Strategic Plan will, in time, have some direct things to say about this.

In the meantime I have written to all the remaining Groups asking for their number estimates in good time so that the events relating to the South of the country can be evaluated and decisions made about their future.

My experience to date shows that many local Groups will be quite unable to fulfil the future demands the Society is likely to place on them: they must learn that the future role which we – and all people with haemophilia – require off them is more relevant than their present activities.

6 **HEPATITIS:** I have held meetings with representatives of Roche and Shering–Plough, manufacturers of Interferon, with a view to obtaining their financial support for publications relating to hep generally and HCV in particular and for a publication which would help our people to understand Interferon therapy, its implications and side effects. I am happy to report that such help appears likely. We must make sure that we cost into such operations our own internal costs and time.

7 **BLOOD PRODUCT RECOMMENDATIONS:** All Executive Committee members will have received the reprint which contains the full recommendations and other comments. Favourable comment is made of our **Essentials** document. While there is a movement towards the use of momoclonal products for those who are HIV+ uptake for other groups appears slower. We need to monitor this situation carefully – if only we had good local representation through our local groups!

ALPHA will have a licensed resin–chromatography product available later in the year [early summer] at a price of approx 24p per unit. This compares with 8Y at 18–19p and monoclonal at approx 48p. Guess which product people are likely to opt for then? What future BPL? Are all high purity products the same? This could, effectively, put England and Wales in the Scottish position – are we happy with that?

It is also interesting to learn that OCTAPHARMA are recruiting staff in the UK and clearly intend to enter the UK market at an early date.

8 **LOCAL HAEMOPHILIA DAYS:** The Doncaster Day went off well and a copy of the Evaluation Paper is attached as Annex 2. The day was very warmly appreciated by all those who took part and local days like this clearly have a role in our activity programme. The total cost of the day was less that the budgeted £2,500. The remainder of the 1992 programme is:–

Saturday June 27 – Bristol
Saturday Sept 26 – Waltham Abbey
Saturday Nov 14 – Newcastle** – this is a change of date and venue.

We need one – at least – member of the Executive Committee to help head up each Day. GRO-D GRO-D and Norma Guy helped in Doncaster and Simon Taylor has volunteered his services. It would be ideal if I could know who would be available for the remaining three dates. Public speaking IS involved in the exercise.

9 **XX CONGRESS WFH – ATHENS: October 1992:** Attached as Annex 3 are the flight and hotel arrangements negotiated through CHAMPION TRAVEL for the Congress. Graham and I will attend at no direct cost to the Society – our costs are hidden in the individual costs for all who participate in our programme. There is a wide spectrum of choice but I fear that our position will mean that we stay in the cheapest hotels available.

Delcgates currently are: Andy Cowe; Simon Taylor; GRO-D; Philip Dolan and Carol Holliday. I am about to book hotels for all those people and would be glad to receive confirmation of my proposal to use cheap hotels.

I am involved with PMSC and EHC presentations at the Congress.

Professor Mandalaki – i/c Athens – has proposed a shrine to outstanding doctors in the history of haemophilia at Athens. A number of us have written to disagree with that position, proposing that we should salute the memory of those who have died from HIV–related conditions. She does not agree with that proposition – the Congress must not be a sad backward looking affair, she says. I share that with the Executive Committee for any views.

10 **EUROPEAN HAEMOPHILIA CONSORTIUM:** The Consortium will meet in Dublin on the weekend 22–25 May 1992. There will be perhaps the largest representation seen so far from European countries at this meeting. It is being sponsored by the aforementioned Octapharma [who process Irish plasma into blood products] and there will be a medical as well as a political content to the agenda.

In connection with European policy on blood and blood products I was due to attend a meeting in Paris on Maundy Thursday. This had to be deferred because of a total transport strike in Paris on that day. The meeting has been re–scheduled for Strasbourg on Wednesday 10 June – the day before my annual summer holiday. The meeting is important and all our participation costs are being funded by an outside sponsor. It is important that we re–affirm our belief that European self–sufficiency is no longer the core issue but that product safety and the development of new technologies have overtaken the self–sufficiency position. Part of the reason for having to be very sure that this is our considered position lies with the aggressive stance being taken by the European Red Cross and not–for–profit sector generally. I have had sight of documents originating from people held in esteem by the Council of Europe and their NMOs which make Hitler's propaganda seem insignificant! Both within the EHC and Europe I can see problems arising. If EHC and the Council of Europe push through a hard line on self–sufficiency I very much fear for the future of haemophilia care within Europe.

11 **VISITS TO CENTRES:** I have made visits since the last meeting to Centres in Glasgow and Manchester and will have visited Aberdeen before the May meeting. In Glasgow, in conjunction with the local Group, I was involved in discussions with the responsible personnel regarding the upgrading of facilities for patients. Although the outcome is not ideal it will represent a massive improvement in patient care areas.

In Manchester Norma and I were discussing the future of the Centre with Dr Guy Lucas [Acting Centre Director] and the future there is now rosier than ever before with few obstacles standing in the way of the appointment of good new staff with sensible budgets for concentrates, etc. It is possible that we may be asked to 'pump–prime' a part–time physiotherapist for the Centre.

My visit to Aberdeen will be concerned with the development of an improved service for people with haemophilia in that widespread and difficult area in the North of Scotland.

All the above visits developed as a result of the residential part of the Scottish Groups exercise.

In addition I have a meeting during May in Staffordshire to discuss problems being experienced by members there. I am attending at the invitation of the local Group.

12 **KATHARINE DORMANDY TRUST:** I have met Sara Cornaby who now looks after the KDT affairs. I am worried that they sell themselves entirely under THE CURE FOR HAEMOPHILIA banner when what they hope to achieve will not represent a cure. It could be churlish of us to raise it formally with the Charity Commission but it is the sort of misrepresentation which the new Charity Act aims to dispel.

13 **PHILIP MORRIS ARTS AWARD:** I circulated details of Mrs Morris' proposal regarding this. The matter requires discussion and resolution.

14 **BIRMINGHAM CENTRE:** Dr Ian Franklin who holds the part-time sessional Directors post at the Queen Elizabeth in Birmingham has been appointed to a post in leukaemia and transplants in Glasgow. He came to see me to discuss the problem facing the future of haemophilia care in Birmingham and the West Mindlands. Eighteen months ago a full time post was approved in addition to Dr Franklin's post. This has not been filled. Following considerable pressure the Health Authority are now advertising both the full and the part-time posts. There will, however, be a time lag with a resultant lack of a Consultant.

The local Group responded emotionally rather than practically to the news.

15 **MEDICAL APPEAL TRIBUNALS:** I have represented a number of cases - less than six - at MATs. They have all been successful - and not always deservedly so!

16 **MONTHLY TEAM MEETINGS:** Members of the Executive Committee may be interested to know that the full staff team meet formally on one morning each month from 10.30am till lunch time. We have outside participants who come and talk about their work from time to time and recently we have had Tudur Williams from the MacTrust and Liz Cox from Positive Options.

17 **FUNDRAISING:** The corporate brochure and Annual Report are on track and progressing to the final article as is new headed notepaper, compliments slips, etc. The logo has been revised and both men are now more or less equal. I hope to have sample material at the meeting on 16 May. Despite many difficulties with Cogent, progress is being made.

The Fundraising Committee will have its first meeting on 12 May when I hope that we can agree that everyone will go away and write to all their chums asking for mega donations for the Society as a first step and to prove how well connected they all are.

McDonalds have done an enormous amount of work on the 1992 fundraising programme and we hope for greatly improved results basing activity on accurate background information which has been painfully extracted from badly kept computer records here and hard copy not previously entered which has been added to the computer data.

18 **VICE-PRESIDENTS:** The Executive Committee were due to report on this to the 1992 AGM. I feel we should do the honourable thing and admit that we have taken very little action on the matter - re-appoint the present Vice-Presidents and ask for a further year to 'look into' the matter.

The Executive Committee are asked to NOTE all sections of this report, apart from pts 3, 7, 8, 9, 10, 12, and 13 which require discussion and or decision.

David G Watters
General Secretary

Paul Burke C:\WPWIN\DAVID\GENSEC.REP 1 May 1992

MEDICAL ADVISORY PANEL

History

The Haemophilia Society has had medical advisors since the inception of the Society. The size of the Panel has varied throughout the years and has consisted, to some extent at least, of "favoured" Reference Centre Directors plus, more recently, other Centre Directors. The Panel did not meet until 1988 when it was felt that advantage could accrue from meeting but over the past three years the usefulness of those meetings has been questioned. There have never been terms of reference for the Panel and this, along with the future direction of the Panel is currently under consideration.

The Current Situation

During the latter part of 1990 it became very clear that from the Society's point of view, there was little benefit accruing to the Society from the meetings of the Medical Advisory Panel. It was decided to "hold" the present position and review the matter throughout 1991/92. The Panel currently comprises eight members i.e.

Prof Arthur Bloom
Dr Peter Jones
Dr Christopher Ludlam
Prof Eric Preston

Dr Brian Colvin
Dr Peter Kernoff
Dr Elizabeth Mayne
Dr Charles Rizza

The problems with the present position were identified as the size of the Panel; the lack to terms of reference; the inability of the Panel members to adjust to an advisory role; the inability of the Society to capitalise on the valuable resource available to it, etc.

Looking For A Solution

The matter has been considered in both Member Services and Policy Committees of the Society and in a project team which reported to an earlier meeting of the Executive Committee. Thereafter the matter was returned to the General Secretary for discussion with Dr E Mayne, the Chairperson for the time being of the Haemophilia Centre Directors (HCD).

A Proposed Solution

Following consultations with the Chairman of the Haemophilia Centre Directors' Organisation and other relevant parties inside and outside the Society, the Project Team now wishes to make the following specific recommendation

The Medical Advisory will be made up of SIX medical members appointed on an annual basis. They will reflect the major current interests and concerns of the Society.

For the year 1992/93 the topics of a major concern are likely to be as follows:-

Product Purity
Prophylactic Treatment

Hepatitis
NHS Reforms

It is important that the interests of members in Scotland and Northern Ireland are recognised in the membership of the Panel. In addition it is desirable that the well-being of those members with von Willebrand's Syndrome and other bleeding disorders be represented in the membership of the Panel.

On this basis it is recommended that the following be appointed:-

Dr Elizabeth Mayne [currently Chair of HCDO]
Professor Arthur Bloom [vWd and scientist]
Dr Charles Hay [Prophylactic Treatment and NHS Reforms]
Dr Christine Lee [Hepatitis]
Dr Christopher Ludlam [Scotland/N Ireland and HIV treatment]
Dr Geoffrey Savidge [Product Purity]

Cont'd over .. /..

Proposed Terms of Reference

1 The Medical Advisory Panel is established to advise the Executive Committee of the Haemophilia Society on matters affecting the treatment and care of people with haemophilia and related bleeding disorders and research matters drawn to the attention of the Executive Committee.

2 Members of the Medical Advisory Panel are expected to give the Executive committee of the Society their best personal and unbiased opinion as distinct from reporting the policy of the Haemophilia Centre Directors' Organisation or any other body with which members of the MAP are singularly or collectively associated.

3 In formulating policy the Executive Committee may seek the advice of the MAP but any resulting policy will be the responsibility of the Haemophilia Society, taking into account that advice along with any other information and opinions available on the subject under consideration.

4 The Haemophilia Society will convene a combined meeting with the Medical Advisory Panel twice in each year.

5 Individual members of the MAP may be asked for specific advice on other occasions, e.g. in relation to preparation of Policy Statements or in connection with any publication programme or in assessing applications for research grants.

6 Individual members of the MAP would be expected to keep the Society informed of developments in their specific areas of interest.

7 The Panel will be Chaired by the Chairman for the time being of the Haemophilia Society or an officer of the Society nominated by that person.

8 The term of appointment of each panel member will be for one year only and appointments will be made at the AGM of the Society.

9 The Haemophilia Society will refund reasonable travel costs to those appointed and attending Panel meetings.

10 The Haemophilia Society retain the right to co-opt as necessary to fill occasional vacancies.

David G Watters
General Secretary

14 November 1991 C:\WP51\DUMP\MAP21

REGIONAL HAEMOPHILIA DAY - EVALUATION

Background

1 Following the success of the pilot haemophilia day in Huddersfield last year, four similar days have been planned for 1992. The first was held on Saturday 29th March at the Swallow Hotel in Doncaster. Arising from the work on strategic planning the Society intends to develop procedures for evaluating the services it provides.

Promotion

2 The event was advertised in the Bulletin (No 1 1992). In addition details were sent to over 800 individual members of the Society living in the Midlands, Yorkshire, Merseyside, Manchester and parts of East Anglia. Staff working in nearby Centres were also notified of the event. Anyone who expressed an interest in attending was sent an application form for completion; those who returned the form were assumed to be attending.

Participants

3 65 people expressed an intention of attending and 56 of these turned up on the day. There was a mixture of pwhs and parents/carers, and a large number of couples. A creche was provided and catered for 8 children. There were participants from a number of Centres including Leeds, Bradford, Hull, Nottingham, Lincoln, Manchester, Liverpool and Northampton. Some participants were not involved in a local Group and this was their first involvement in Society activities.

4 There was no charge to participants; lunch and tea/coffee were also provided. Participants had to make and pay for their own travel arrangements.

Administrative arrangements and venue

5 The administrative arrangements and venue facilities were valued positively although there were some adverse comments about access to parking facilities, no map of the hotel location, cold coffee, cold hall and no vegetarian alternative for lunch. The creche facilities were praised.

Content

6 The programme consisted of state of the art lectures (Haemophilia and Haemophilia and HIV), workshops (Hepatitis, Quality of Care, Physio/Orthopaedics and Living with Haemophilia) and a Rap session.

7 An evaluation form was completed and returned on the day by 55 of the participants. The attached table shows the participants' evaluation of each element of the programme. Clearly all were very successful with the possible exception of the rap session.

8 The comments on what people got out of the day mainly focused on getting new information and increased understanding, making contact with others, hearing what happened in other Centres, hearing about others' experiences.

9 Most comments on how the day could have been improved suggested more time for the workshops and discussion.

Costs

10 Major items of expenditure were the hotel and food, expenses for 6 speakers/workshop leaders, promotional mailing to 800 members, 2 staff members staying overnight and on the day, and staff time in organising and preparing the day. The cost was estimated at £2,500 but the actual cost has not yet been calculated.

ISSUES FOR CONSIDERATION

1 Those who attended found it very useful; however less than 70 out of 800 members individually mailed showed an interest.

2 Would more have attended if they had not had to travel so far? If it had been too local the benefits of hearing what happened in other Centres would have been lost. What is the most appropriate area to cover?

3 Should a small fee be charged, at least to cover the cost of the food and refreshments? Would a fee deter people or encourage them?

4 More information about who attends would be helpful. Future application forms could seek the following information :-

Centre attended
whether (active) member of a local Group
pwh/parent/other carer
haemophilia A/haemophilia B/von Willebrands
severe/moderate/mild

GB 2.4.92

Participants Evaluation of Haemophilia Day Conference

	Very useful	Useful	O.K.	Not useful	Not at all useful
Haemophilia Lecture	25	9	4	0	0
Haemophilia and HIV Lecture	13	3	1	0	0
Hepatitis Workshop	12	4	0	0	0
Quality of Care Workshop	18	2	1	0	0
Physio/Orthopaedic Workshop	8	4	6	0	0
Living with Haemophilia Workshop	19	5	1	0	0
Haemophilia and HIV Workshop	11	4	2	0	0
Rap Session	16	16	11	2	4

Paul Burba C:\WPWIN\GROUPS\EVALUATE.1 1 April 1992