

**CONFIDENTIAL**

General Secretary's Report

to

The Executive Committee

February 1990

The Haemophilia Society  
123 Westminster Bridge Road  
LONDON  
SE1 7HR

2 February 1990

- [01] ADVERTISING COSTS: Since the last meeting we have received a County Court Summons in connection with unrequested advertising carried in a financial journal during 1987! We have corresponded with the journal on a large number of occasions and never received any response. The matter was placed in our solicitors hands and suffice it to say that the matter has now been withdrawn from the County Court and the discussion is about who bears our legal costs - I do not see why we should!
- [02] ANOTHER DISPUTED ACCOUNTED: In connection with the tendering for the HEA-funded booklet on Safer Sex, an indication was given, verbally, ~~by one of the unsuccessful companies~~ last September by one of the unsuccessful companies that they would invoice us for their costs. We immediately wrote pointing out that there had been no such agreement and stating that we would not see ourselves liable for any demand for payment. We heard nothing more until the Christmas period when we received a peurile Christmas card saying 'We would wish you ..... if you had paid ...' etc. I responded with a letter stating that as far as we were concerned we had not received an invoice and, further that our letter to them had clearly set out our understanding of the matter. I have now heard from them again with a similar childish letter and as a consequence I have referred the matter to our solicitors, having advised them that I have followed this course. [The total amount involved is around the £125 mark!]
- [03] FRANS HALS: As reported last month, the early view of the Frans Hals Exhibition was held at the Royal Academy on Tuesday 16 January in the presence of HRH The Princess Margaret. The event was organised by CRUSAID and a great deal of credit for our benefit from this event is due to Jonathan's efforts. It is not known what the final benefit to the Society will be.
- [04] USE OF VOLUNTEERS: During the month I had a visit from a member from the London area who was keen to be used as a visitor to people with haemophilia and HIV/AIDS. Her own son - or was it her husband - has only fairly recently died. I can see difficulties in our setting up a volunteer structure like this with our limited resources. Ideas?

- [05] ALL PARTY AIDS GROUP: I attended a meeting of the Group on January 23 when we considered media responses to HIV/AIDS especially in relation to the Kilbracken school of thought - ie, HIV/AIDS does not affect heterosexuals. It was agreed that a Committee of those involved in media relations in the relevant NGOs should form a Committee to study this. However, while I am only too willing to do this, it strikes me that National AIDS Trust was set up to handle this very situation and I have voiced the view that they should be forced to take this one on and forced to get it right (for a change!).
- [06] IRISH HIV LITIGATION: I met the Irish solicitor involved in litigation in the Republic on 24 January. Their approach is slightly different: the benefot of a small country and one firm of solicitors is apparent!!
- [07] THURSDAY 25 JANUARY: I was due to attend a meeting of the Birmingham Health Authority with representatives of the local Group of the Society on this day but while waiting for a train which never arrived at Euston it became clear that it would be folly to leave London on that day. I returned to the office and sent the staff home early in common with most offices in town. We sustained only minor damage to the room of the mezzanine level.
- [08] CERT: I attended the meeting on Saturday 27 January which has reported to this meeting of the Executive Committee.
- [09] TRIBUNALS: During the month I attend x3 Tribunals on behalf of members of the Society. I won (easily!) x2 Mobility Allowances and was granted an adjournment in another case where the appellant was unable to attend.
- [10] AIRLINES BALL: It appears that there may be no more events organised by this Committee. The Royal Albert Hall have excluded the Ball from their dynamic new marketing programme. This clearly leaves a gap in our fundraising budget for the coming two years. However, if it is decided to abandon the Committee altogether, the Society will benefit from the balance held in the account (about £12,000 I think).
- [11] PARLIAMENTARY LUNCHES: After a hiccup, those begin on Wednesday 7 February when AJT and I will 'entertain' John Home Robertson, Eric Heffer, Jim Cousins and David Young - all Labour MPs - to a sandwich lunch here at 123. They will follow at fairly regular intervals up to Easter. We will also be using Simon Taylor on some occasions when AJT is not available.

- [12] ANNUAL REPORT: Thoughts/ideas for the Annual Report should be communicated to Andy or the General Secretary as a matter of some urgency. AC and DGW will be discussing broad draft this coming weekend (10 Feb) in Edinburgh.
- [13] THE HOSPITAL SATURDAY FUND have announced that we are to receive a donation towards the cost of our holiday projects. I have been invited to attend an event to celebrate their 200th Anniversary on 19 February in order to receive their cheque.
- [14] STAFF: Staff levels can on certain days be low at present. Jonathan is in Canada doing the WFH document (latest reported date of return in 7 March 1990). Paul is off during the week commencing 12 February and Linda the following week - she and Richard will be married on Saturday 17 February.
- [15] ANNUAL GENERAL MEETING: After discussion with the Chairman the 1990 AGM will be held in Sheffield. Because of the lateness of the hour the topic for the afternoon lecture has also been finalised. The Speaker will be Geraldine Mulready, a psychologist, who is a recognised expert on STRESS which will be the topic of her paper. JPC and DGW experienced her lecture in Dublin at the AGM of the Irish Society and felt it was most worthwhile!
- [16] EXECUTIVE CONFERENCE: In view of the fact that I received no adverse responses to my Memo concerning a change of date of the above event, it will now be held over the weekend October 5-7 1990. I have also advised Armour of this since they will be funding the event.
- [17] INDUSTRIAL SOCIETY: On Tuesday 23 January, Roger O'Connell from IS Voluntary Services Division spent the day at the office assessing our Management Training needs. A full report will be received within the next four weeks which will set out the programme for the two day conference on March 13 and 14 1990.
- From a personal point of view I would have to say that in whatever areas the Society may have succeeded over the past three years, it has not succeeded in developing effective management and communication with staff - and that it maybe more my failing than the Executive Committee as such. The past three years has seen what would have been a totally unthinkable growth in staff and demands from members!
- The IS fee for the assessment at the Conference is £1075 plus VAT. The cost of the accommodation etc will also be down to us.
- [18] WHO/USA BOYCOTT: Immediately after the last meeting I wrote to Dr Jonathan Mann setting out our concern that WHO were not following their own Charter. Needless to say I have not received a reply!

- [19] USA BOYCOTT - Part II: At the last meeting it was agreed that we should not sign the UK AIDS Charter IF those bodies who signed intended to travel to the USA to attend, for instance, the IAC. I would like to suggest that it would be good tactics to vary that decision! It has already caused one or two organisations to change their minds and the only remaining organisation still intent on making the trip appears to be the National AIDS Trust.
- I am firmly convinced that the Charter is more important than NAT and, in consequence, I recommend that we agree now to sign and allow anybodies who do travel to work out how they will express their protest.
- [20] THE NHS REVIEW: I have circulated copies of letters received in response to correspondence sent out some time ago to a variety of Ministers, etc. I included within the circulation the MAP. They have expressed deep concern about the content and will discuss the matter in detail at their forthcoming Regional Directors' Meeting.
- [21] VISIT BY WFH PRESIDENT: Members will have noted that this will not now take place.
- [22] PORTON PRODUCTS: On January 24, Linda, Heather and the GS attended a pleasant function at the Cafe Royal at which the Directors of Porton Products presented the Society with a cheque for £500. This was as a result of a survey of Centres which they carried out with the promise of £s to the Society for each completed form received. They will be making another donation later in the year.
- [23] 123 WESTMINSTER BRIDGE ROAD: Our Surveyors have informed us that those acting for the British Railways Board are about to propose that our lease be renewed in the annual sum of £29,000 - ie £25 per sq ft. They are naturally contesting this and hope to end up with a more reasonable figure.
- The Executive Committee should consider what they wish to do if those representing BRB do succeed! Should we begin a preliminary search again for other offices?
- [24] USA BOYCOTT - Part III: The European Parliament will be debating a Motion deploring the actions of the USA on limitations on entry for those who are HIV positive.
- [25] HNA Video: P&ER may well report on this. The video has been viewed and is satisfactory. We are suggesting training notes to accompany the tape itself.

- [26] Dr ROBB SMITH: Further to last months brief discussion he has now written suggesting that he has received a large number of donations which will enable him to begin publication and further suggesting that a token contribution from the Society would enable him to thank us too in the Preface. I hope that he would thank us anyway since we have spent many man hours helping him with the text!! However, a small contribution may show our appreciation of Professor Macfarlane.
- [27] EUROPEAN CITIZEN ACTION: The Des Wilson Citizen Action set up are about to open ECAS(ervice) for NGOs. The main purpose of the organisation is to facilitate voluntary groups making representations to the European Parliament. Facilitation is, as usual, provided at the level you pay for! From a UK point of view we would certainly benefit from membership. From a European Consortium point of view it is vital that we join. Ordinary Membership costs 1200 ECU per year - this provides office space in Brussels, hlep with contacts, monthly lobbying publication about the EEC, leislative and other developments,etc. FULL membership costs 4300 ECU per year and, in addition to the above is a personalised service and a permanent watching brief covering all items in priority areas - eg 'health' and so on. My view is that we should become Ordinary Members in the first instance and if necessary become Full members at a later date and in consultation with our European colleagues.
- [28] HEPATITIS: Following the last meeting I wrote to Dr Rizza about the hep problem and the possibilities of compensation etc. Dr Rizza needs time to consider his position on this in view of the current litigation and will discuss the situation with Regional Directors and their lawyers. In the meantime we could possibly put a short piece in UPDATE seeking those who have been caused severe liver damage as the result of their use of blood products?
- [29] **FINALLY** I apologise for the lateness (and quality of typing) in this report. I also apologise for the delay in getting out the Minutes. This is not entirely due to the office!
- [30] REORGANISATION OF 123: IF we are to stay on at 123, in view of the committee room becoming an office, we need to look further at reorganising available space. We are currently thinking in terms of changing the present kitchen into a small meeting room (6-8 people) and putting a kitchen/staff area into the small cellar. I simply ask that this be noted at this meeting.

## **SUMMARY**

The Executive Committee are asked to:

ACCEPT this Report and, in particular:-

**DISCUSS** item [04] - The Use of Volunteers

**APPROVE** item [15] - AGM Venue and Topic

**APPROVE** item [17] - Staff Training Costs

**DISCUSS** item [19] - UK AIDS Charter

**DISCUSS** item [23] - Premises

**DISCUSS** item [26] - Dr Robb Smith

**DISCUSS** item [27] - ECAS

David G Watters  
General Secretary

February 1990