

CONFIDENTIAL

GENERAL SECRETARY'S REPORT: November 1989

**The Haemophilia Society
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- [01] **COMPENSATION:** Once again issues relating to litigation in the High Court and the campaign for an out-of-Court settlement by the Government have occupied prime place in my priorities. This applies equally to individual cases and advice and to the lobbying campaign. Members of the Executive Committee already know what took place in the High Court on Monday 23 October 1989 and are also aware that letters have now gone to all MPs who are active in the House and to a large number of Peers as well as Bishops. In addition there has been a large amount of media interest in all mediums - newspapers, radio, tv. All in all this has been a demanding period and work as 'Press Officer' has been enough to keep one fully occupied. I will be happy to answer questions at the meeting but can see little point in reciting all that I said at the Council meeting on 29 October in Newcastle.
- [02] **RECOMBINANT FACTOR VIII:** On 15 September we were visited by a young boy and his parents from Bradford. The boy has been treated exclusively with synthetic factor VIII since birth.
- [03] **JAPANESE GOVERNMENT DELEGATIONS:** Which government send more delegations to the UK Society than any other? Well, the headline gives the story away. I spent one afternoon with a rather jolly host of non-English speaking Japanese government officials looking into haemophilia/HIV/AIDS/Compensation issues. (I had already done one and there is yet another in the pipeline!).
- [04] **ARMOUR PHARMACEUTICAL CO** Members of the Executive Committee will realise that Armour are very much about the business of improving their public image in the UK prior to obtaining a full product licence for MONOCLATE. I have spent more than a little time with them discussing issues - and extracting money - eg I understand that they are willing to grant £10,000 for publications costs; that they are keen to meet travel costs to lobby the US Congress; that they are looking into funding the 1990 Executive Conference; and so on. However, this is time consuming and reminds one of the 'there's no such thing as a free lunch' maxim!!
- [05] **CHEQUE PRESENTATION:** After the Council meeting on 23 September I attended the Portcullis Club in Caterham (Kenley Aerodrome for those who are interested) to receive a cheque for approx £700 from some soldiers - one of whom has a toddler with haemophilia. It was a good evening and they intend to run as a team in the London Marathon for us in 1990

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- [06] **PMSC BUSINESS** On Monday 25 September I met Bob Shearer in Geneva to go through some WFH Congress papers - and also discussed the USA Visa position. I stayed overnight and returned early on Tuesday 26 September.
- [07] **EUROPEAN PARLIAMENT:** Jonathan Cooper and I have held a meeting with Ken Collins, a UK MEP who is also Chair of the Environment Committee. In addition I have written to all MEPs in the UK and to all the relevant Committee members who are likely to be useful to us on any future matters relating to blood products, HIV/AIDS and related issues. They have all been very warm and encouraging in their responses.
- [08] **VICE PRESIDENTS:** Close contact has been maintained throughout the period with our Vice Presidents in Parliament and I have met Frank Field, Baroness Masham and Robert Key. It was particularly useful to meet Robert Key who is now a PUS and therefore not able to be as forthcoming as in the recent past. However he is full of support for our cause and is keen to help. This also applies to the other two naturally.
- [09] **HCD ANNUAL MEETING:** Ken Milne attended this meeting but for some unknown reason Peter Jones arranged for me to go and present our compensation campaign after lunch. I must say that I found the trip a waste of time and that PJ is not as helpful as he has been in the past. I recommend that we use Dr Mark Winter for our crusading meeting in the House on 30 November!!
- [10] **EXECUTIVE COMMITTEE CONFERENCE:** Apart from expressing the appreciation of the staff for sharing in the weekend it is not necessary to report further. A report was circulated in time for the Chairman's Conference.
- [11] **IRISH SOCIETY AGM:** On the weekend after the Executive Conference Jonathan Cooper and I attended the AGM of the Irish Society in Dublin. They had a most interesting meeting and I was especially impressed by Dr Paula Bolton-Maggs on genetic choices and Geraldine Mullready on Stress. Dr Charles Hay (Liverpool) also spoke.
- [12] **MEDICAL ADVISORY PANEL:** The panel met on Friday 20 October and included within its agenda a presentation of Monoclate by Armour Pharmaceuticals. Other agenda items included compensation, hepatitis, HIV, blood products, Europe, etc. A full report is within the remit of T&C.

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- [13] **NORTHERN IRELAND AGM** I will be attending this meeting on Saturday 4 November in company with Terry Fitton. I have been asked to speak on 'The Society: Where we are going'. Things in the Province are not easy with a great number of different and sensitive issues around. We hope that we can have a productive time there.
- [14] **STAFF MANAGEMENT TRAINING:** The VOD of Industrial Society are due to have a preliminary meeting on Monday 6 November but we doubt if there will be anything to report further at the meeting. **Dr Norman Keir** did suggest an Ashbridge course for the General Secretary. Those last a month and from time to time free places become available.
- [15] **WHEN THE CAMPAIGN LOOSES STEAM - if it does!** A charitable Trust are prepared to look at funding a worker who will open up media opportunities if it is necessary to extend the Campaign beyond the turn of the year. Simon Taylor is looking at the possibilities for this so that we are ready to swing into action at an early date in 1990!
- [16] **EXECUTIVE COMMITTEE MANAGEMENT TRAINING:** I am having a very preliminary meeting with Charity Recruitment to look at the possibility of introcing this at either the Spring Day in 1990 or the full Executive Weekend in the Autumn of 1990.
- [17] **AIRLINES BALL:** Friday 24 November 1989: tickets available to those members of the Executive Committee who wish to attend.
- [18] **MERSEYSIDE AIDS SERVICE:** I have been asked to speak at an AIDS Service in Liverpool Parish Church on Saturday 25 November. This will restrict my activities on Friday 24 considerably!!
- [19] **CHRISTMAS ARRANGEMENTS:** This being the last full meeting before Christmas, Executive Committee members should note that the office will be **closed from Monday 25 December to Monday 1 January 1990 inclusive.**

Although this report is a great deal shorter than usual I would re-assure any members of the Executive Committee that the past two months have represented the very busiest period of my working life with the Society!!

David G Watters
General Secretary

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[20] **THE USA, HIV AND VISAS:** A confidential exploratory proposal from Alan Brownstein has been circulated and I would be glad to hear response to that at the meeting on November 9 rather than necessarily in writing. The Chairman will also wish to clarify his own position if that is not already enclosed with this report.

[21] **JOHN PROTHERO:** I wanted to mention that the Fund in memory of John has already attracted a large number of donations and will be used to provide equipment for the new Centre at St Thomas' Hospital. Please direct all donations through the office.