

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

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INFECTED BLOOD INQUIRY

WITN6392203



MINUTES OF A MEETING OF THE MEMBER SERVICES COMMITTEE
HELD ON SATURDAY 23 JANUARY 1993 AT 11.00 AM
AT 123 WESTMINSTER BRIDGE ROAD, LONDON SE1

Minute No

Action

Present: Mr K Milne (Chairman), Mr J Lander, Mrs N Guy,
Mr R Dickason

In attendance: Mr D Watters (General Secretary), Ms R Benson (Minutes
Secretary)

MS93.01 Apologies for absence

Apologies for absence were received from Dr M Winter and Ms Liz Cox,
Barnardo's Social Worker.

MS93.02 Minutes of the meeting held on 10 October 1992

In the minutes of the meeting held on 10 October 1992 Mr Milne requested that
minute MS92.38.3 should read " The local Group had made a formal complaint to
the Social Work Department about the time given to HIV/non-haemophilia
problems, rather than to those connected with haemophilia alone." (Previously
"time given to HIV/haemophilia problems..") Otherwise the minutes were
proposed as an accurate record of the proceedings by Mr Lander, seconded by
Mrs Guy, and agreed unanimously.

MS93.03 Matters arising

03.1 Memorial and Thanksgiving Service [MS92.38.1]: Mr Watters reported
that the Thanksgiving Service had taken place on Saturday 31 October and had
been well attended, with people coming from the furthest parts of the country. Mr
Watters said that the Chairman felt that two Services in 1993 might be a good idea,
one in London and the other perhaps further north. The Committee approved and
Mr Watters said he would keep everyone informed; Mr Dickason offered to
investigate possible locations for the out-of-London service.

DW

Mr Milne noted that St Botolph's Church was still undergoing refurbishment, and
it would be several months before the practicalities of the memorial could be
thought about.

03.2 Letters of consent for treatment [MS92.46]: Regarding the request by a Consultant at Birmingham Children's Hospital that patients and parents of patients sign a letter of consent for treatment, Mr Watters said that there had been no further developments. The Committee agreed to keep an eye on the matter. It was also reported that the Consultant at the Children's Hospital had refused to treat two children who had continued legal cases.

DW

03.3 Social Worker Post at Margate [MS92.38.3]

Mr Milne reported on the situation that had arisen at Margate Haemophilia Centre. The local Group had lodged a formal complaint about the Centre's Social Worker and what patients regarded as the excessive amount of time she gave to non-haemophilia/HIV problems. Canterbury and Thanet Health Authority was to conduct a disciplinary hearing. Mr Milne said that the problem might be resolved by the possibility of the transfer of the Centre to Canterbury and the creation of different or new social work posts. The Committee noted the matter and agreed that the outcome of the hearing should be awaited.

DW

03.4 Dr Helena Daly, Truro: Mr Watters reported that Dr Daly

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MS93.04 Positive Options

Mr Watters reported that Ms Liz Cox's contract with Barnardo's had been renewed, and that the post would be funded by Barnardo's irrespective of whether or not South East Thames Regional Health Authority chipped in. Mr Milne felt that Mrs Cox should be issued with another invitation to a Member Services Committee meeting to speak about her work. This was agreed.

DW

MS93.05 Events

05.1 Haemophilia Days: Newcastle: Mr Watters reported on the Haemophilia Day in Newcastle, and said that while it had been successful he thought it had not been needed as much as it might have been in other areas. It had been one of the Society's more inexpensive Haemophilia Days, costing under £1,500.

05.2 Haemophilia Days 1993: Mr Watters reported that there was a possibility of sponsorship from a charitable trust for a programme of Haemophilia Days in 1993. The Macfarlane Trust had agreed to co-operate with the Society over such events, but was prepared to provide only £500 per day. Mr Watters proposed that in setting up future Haemophilia Days haemophilia and HIV workshops would be held on the same basis as haemophilia workshops in the past. The Day would be offered initially to Birmingham, perhaps in the autumn. The Committee agreed that this should be followed up if sponsorship appeared.

DW

MS93.06 Publications

A proposal by Health Network had been circulated outlining various options regarding the publishing schedules and contents of both *The Bulletin* and *Update*.

The Bulletin: The Committee was in agreement that technical articles on medical subjects should no longer appear in *The Bulletin*. Mr Milne expressed concern that Centre Directors' interest in *The Bulletin* and perhaps, the Society, might be diminished, but Mr Watters expressed the view that the Society's relationship with Centre Directors was now well established and understood by all concerned, so that the need for technical/medical "carrots" was no longer there. Mr Dickason thought that *The Bulletin* should not be a pale imitation of the medical journals from which doctors got latest information. Mr Milne accepted these points and said that the professionals could still be asked to provide articles, but that the editorial board should be adamant that these be understandable to the layman. Mr Dickason suggested that the publication be re-launched as a vehicle for member readership and that an annual index be provided so that people could look up information in back issues. Mr Watters suggested that the Society might offer for sale binders for back copies. He suggested also that the Society do a readership survey asking people what they thought of *The Bulletin*.

Update: Mr Dickason observed that *Update* had started out as a replacement for *Haemofact*, conveying urgent news, and there was agreement that the frequency of its publication could be reduced. Mr Dickason thought that it needed a re-vamp and a change of title, making it obvious that it carried the latest news. The Committee discussed and agreed the idea that *Update* be cut to two issues a year, and that the money saved be devolved to the production, in-house, of a publication projected at opinion formers, such as MPs, health authorities, NHS Trusts. The mailing list for opinion formers was 6-700 addresses. Mr Watters said that the cost of producing *Update* four times a year was approximately £500 and sponsorship had not yet been found for 1993. By reducing the number of its appearances and incorporating the proposed new opinion formers' publication within *Update's* projected budget, sponsorship might be made to look more attractive, since potential sponsors would want to be known to opinion formers.

Publishing schedule: After some discussion the Committee arrived at a suggested publishing schedule for the two main publications: *The Bulletin* to appear at the end of February, July and November, and *Update* to appear at the end of April and September. It was suggested that the publication for opinion formers appear twice a year.

The Committee agreed to recommend the points of agreement above to the Executive Committee.

KM

MS93.07 Grants

07.1 Report on 1992 Grants: A report had been circulated showing grants made during the period October to December 1992, and also the total grants made for the years 1991/92 for comparative purposes. The Committee noted the report.

07.2 Grants Policy (Draft): Mr Watters had produced a Grants Policy in draft and circulated it to members of the Committee. He said he had not had much response. Mr Dickason said that, as with the Health Network proposals on publications, it was very useful to have papers in advance of meetings as they enabled those concerned to make informed decisions. He said that the information received in this way was much appreciated, even though sometimes those who had written the papers felt they got little feedback. The policy was agreed and at Mr Watters' suggestion it was agreed that it would be circulated to a small number of Social Workers for comment and eventual submission to the March Executive

Committee for full approval.

MS93.08 Hepatitis

08.1 Booklet: Mr Dickason reported on the latest version of the Hepatitis Booklet. It had been submitted to Drs Hay and Preston; Dr Hay had responded, Dr Preston had not, and the Booklet had been printed. Subsequently Dr Preston had suggested a complete re-jig, but Mr Dickason felt that, on balance, the text could stand. He said the purpose of the publication was to communicate with people who did not read medical journals and it was not necessary to be always mathematically correct. The Committee agreed.

Regarding Hepatitis A, Mr Dickason said that the advice so far was that the Society should not make an issue out of it as the virus did not occur often in people with haemophilia. Hepatitis C, however, could be sexually transmitted, and he thought this important enough to warrant a notice in *The Bulletin* as well as reporting in the Booklet. The Committee agreed.

08.2 Octapharma, Vienna: Mr Watters reported that he had visited Octapharma in Vienna along with other European Haemophilia Consortium members in connection with HAV in product. While no conclusions could be drawn, the company was looking very carefully at the issue and a full report would be available soon.

MS93.09 Strategic Planning

Mr Watters reported that in discussion with Mr Barker they had agreed that until the end of March Mr Barker would set aside every Wednesday solely for Strategic Planning work, and that secretarial back-up would be available to him. The Committee approved.

MS93.10 Staffing

10.1 Present situation: Mr Watters reported that the Member Services managerial situation was almost resolved, and he was awaiting written confirmation. He would keep the Committee informed.

10.2 Future arrangements: Mr Watters reminded the Committee of the plan to merge the Members Services and Policy and Development Departments. He said that he and Mr Barker had arrived at a satisfactory arrangement, whereby Mr Barker dealt with work relating to services provided by external bodies, and Mr Watters handled matters to do with services provided internally by the Society. This was endorsed by the Committee.

DW

MS93.11 Revision of HC(76)4

The latest revision of the Department of Health's document HC(76)4 had been circulated to the Committee in advance. Mr Watters reported that it was to be distributed to professional bodies for consultation. The Committee agreed that the document was the best the Society could have hoped for. Mr Watters said that this commendable result was because the Society had campaigned hard and had been seen to be out and about.

MS93.12 DHAs, Contracts and Funding

Mr Watters reported that St Thomas' was £2,000,000 in debt because District Health Authorities had not paid for services provided by the hospital. The issue was to be debated in Parliament on 26 January 1993 and the Society had mailed a Press Release to Members of Parliament. The Committee noted the matter.

DW

MS93.13 Local Groups

13.1 Perth Group: Mr Watters reminded the Committee that the Perth Group had not submitted either accounts or bank statements in relation to the past few years, despite several requests to do so from the national office. He said that he had written recently to inform the Group that he would be proposing suspension unless they complied. Mr Milne observed that the Charities Act of 1992 disallowed discretion in such matters; the Society was obliged to insist on observance of the rules. Mr Dickason offered to provide material on the circumstances under which a local Group might be suspended; he had compiled this during a similar skirmish with a local Group. The Committee accepted his offer and endorsed Mr Watters' stand, who said he would keep members informed.

RD

DW

13.2 Birmingham Group: Mr Watters reported that the national office had declared Birmingham Group's AGM, fixed for 12 January 1993, null and void because they had not properly notified all the local members, but had relied on a notice posted at their Christmas Party. The national office would be sending out notices for a new AGM date and would ask for nominations for the post of Chairman.

DW

MS93.14 Any Other Business

14.1 Centralised banking: Having discussed local Groups, the Committee wished to recommend to the Executive Committee that the Society adopt a policy that all local Groups should be in centralised banking, and that this should be accomplished by the end of June 1993.

KM

14.2 Mr Watters raised the issue of Armour's sponsorship of Armourpagers, a sum of £38,000 a year. He had recently discussed ways of reducing this cost with the company: the setting-up costs were high, and the subsequent running costs were relatively low. Several pagers (£65 each) had been lost by their owners. Mr Watters suggested to the Committee that a way of keeping down expenses would be for people to pay their own quarterly hiring bills. The Committee agreed.

DW

14.3 Disability Living Allowance: Mr Milne asked for clarification on the latest situation regarding the Disability Living Allowance. Mr Watters said that the national office was giving people help and full explanations on the ins and outs of the DLA, and most people received it on a letter from himself accompanying the necessary forms. Mr Milne suggested a reminder that the Allowance was available be put in *The Bulletin*, and this was agreed.

DW

14.4 Motability: Mr Milne asked for an update on Motability and insurance matters. Mr Watters explained that drivers would be transferred to the new insurance company when their present cover expired. The Committee was assured that people would be adequately insured with the new arrangements.

MS93.15 Date and time of next meeting

The next meeting of the Member Services Committee will take place on
Tuesday 20 April 1993 at 5.30 for 6.00 pm at 123 Westminster Bridge Road.

DW/RB 25.01.93