

**Summary of activity at official level regarding the revised donor leaflet on AIDS:  
October 1983 – August 1984**

Purpose of this note

1. Questions 43 – 48 of the Rule 9 Request for Lord Glenarthur concern the revision of the donor leaflet on AIDS. The purpose of this note, which has been prepared by Lord Glenarthur's legal team, is to provide a factual overview of the activity at official level on this topic during the period October 1983 – August 1984. What follows below is reconstructed from the available record of communications passing between officials. It is intended to be a neutral, chronological presentation whose contents can be verified from the source documentation.

October 1983

2. The minutes of the first meeting of the CBLA's Working Group on AIDS in relation to blood transfusion held on 14 October 1983 [PRSE0002573] record a discussion of the AIDS leaflet. Approximately half of the RTCs were distributing the leaflet with the call-up card/letters whilst the others were either making the leaflets available at sessions or were actively handing them to donors at sessions. In general, the Group considered that a uniform system of distribution would be advantageous and it was noted that RTCs had been asked by the DHSS to report on the distribution at the end of November 1983. Dr Lane expressed the view that persons experienced in marketing or advertising would be able to give advice on getting the information to the public and their methods may be more effective. It was agreed that:
  - a. Special clinics should be included in the distribution;
  - b. Health Education Councils should be approached;
  - c. Gay Societies should be contacted;
  - d. Comments on the leaflets from donors might be invited.
3. With respect to the content of the leaflet itself, it was considered that the important message as far as the blood donors were concerned, namely not to give blood if they were in a high risk group, should be highlighted in some way. It was agreed that the above matters would be raised at the DHSS on Monday 17 October 1983, when the Advisory Committee on the NBTS met.

4. The minutes of the Advisory Committee on the NBTS are at **[CBLA0001763]**. They note that a leaflet had been produced by RTCs and the DHSS, and also that a similar message was contained in an information leaflet issued by the Gay Medical Association. However, there is no record that the specific issues raised at the earlier meeting of the CBLA's Working Group were raised.

#### November 1983

5. It appears that Mr Winstanley (DHSS) first made enquiries, by phone, at the end of "the three-month trial period". See the letter dated 23 November 1983 from the Wales Regional Transfusion Centre to Mr Winstanley, reporting on the use of the leaflets **[DHSC0002237\_014]**.
6. Also on 23 November 1983, Dr Wagstaff (Director of the Regional Transfusion Centre, Sheffield), wrote to colleagues asking for information about the distribution of the AIDS Leaflet. (The existence of the letter can be inferred from **[WITN5282008-001]**; see para.9 below).

#### December 1983

7. From **[PRSE0002899]** it can be seen that in 1983, the Scottish National Blood Transfusion Service had adopted the approach of having the leaflets available at donor sessions. The minutes of a meeting of the SNBTS on 8 December 1983 state that "*it was agreed that a more active approach would be acceptable now*". The question of revisions was also raised; see the drafting suggestions that were sent to Dr Wagstaff in January 1984, below.
8. At this time, there is correspondence within the DHSS on the topic of ensuring the leaflet was made available at STD clinics: see the letter dated 19 December 1983 from Dr Sibellas, which followed Ministerial approval of this proposal **[DHSC0002237\_022]**. (The MSSVD was the Medical Society for the Study of Venereal Diseases; see further the minute from Dr Sibellas to Dr Smithies on 8 February 1984, below).
9. Following Dr Wagstaff's letter of 23 November 1983 (para.6 above), replies were received; one example is enclosed at **[WITN5282008-001]**, where there is a letter dated 2 December 1983, from Dr Darnborough of the Cambridge RTC.

#### January 1984

10. It is apparent that Dr Wagstaff compiled the answers received into a table and sent it back to the DHSS (Mr Winstanley) under cover of a letter dated 3 January 1984 [WITN5282008-002]. Dr Wagstaff noted that “*one or two people expressed a view that there should be a revision of the content before reprinting*”, so the issue was not merely of supply and reconsidering the means of distribution. Dr Wagstaff referred to developments in Scotland, stating that Dr McClelland (Director of the Transfusion Centre in Edinburgh) was re-writing the leaflet to take account up-to-date views. He hoped that a draft would be available for discussion at the next meeting of the Regional Transfusion Directors on 25 January 1984, after which Dr Wagstaff would contact the DHSS again.

11. On 10 January 1984, Dr Wagstaff received drafting suggestions from Dr McClelland, who enclosed a “slightly re-worded” version of the AIDS leaflet. Dr McClelland added:

*“I really have to emphasise that the suggested changes are mine and mine alone. They haven't yet been discussed with the Scottish Transfusion Directors, Harold Gunson's AIDS Working Party of the CBLA sub-committee, the Transfusion Directors Hepatitis Working Party, or any of the other numerous groups who appear to be concerned with this problem. I will be discussing these proposals with the Scottish Directors on 17th January and also sending them to Harold in the near future, so I hope that his Working Party will discuss them at the end of January.*

*The changes I have made are based on discussion that I have had with my colleagues here, with people in the States and in particular I have lifted a number of ideas from the leaflet which is used in the New York Blood Centre.”* [PRSE0000351], subsequently followed up by the SNBTS in March 1983, [PRSE0003405].

12. The minutes of the RTD meeting on 25 January 1984 [NHBT0018332] record, briefly, that Dr Wagstaff reported that RTDs had indicated that no offence had been caused to donors “regarding the introduction of the AIDS leaflet at sessions.” There is no record of discussion of the revisions to the leaflet.

#### February 1984

13. On 8 February 1984, Dr Sibellas wrote a minute to Dr Smithies picking up the subject of distribution to STD clinics. She noted there appeared to be a “*low-key approach to distribution [of the leaflet, to STD clinics] already taking place*” and said that RTDs would soon need more

copies, “preferably the amended version when the others have run out” [DHSC0002239\_010]. Someone (not Dr Smithies) annotated this note asking Alun Williams (Director of the National Blood Transfusion Service) “what is the amended version?”.

14. On 14 February 1984, Dr Smithies wrote to Mr Williams [DHSC0002239\_015] saying:

*We have briefly discussed the need for the current AIDS leaflet which is distributed by Regional Transfusion Centres to potential donors. In view of the published evidence of transmissibility of AIDS by blood transfusion, our current advice to donors could seem too lax. It may also be necessary to take up with the Transfusion Directors the need for more positive distribution rather than the negative approach that some of the Centres have used.*

*I would be grateful for an indication of how soon a re-print of the leaflet will be required. If this is fairly soon I should be discussing the re-draft with Dr Gunson and the RTDs. If, however, there are many more leaflets still available we may need to consider whether we should substitute the re-draft before they are used up.*

#### March 1984

15. On 6 March 1984, Dr Smithies wrote to Dr Sibellas [DHSC0002239\_038], saying:

*As you know we are going to revise the pamphlet that has been circulated to blood donors and is available at blood donor sessions. However, we really need to reach the high-risk group at source and I would therefore like to propose that included in the advice given in the leaflet currently being drafted by the HEC should be some advice on blood donation.*

*For instance:-*

*“If you wish to donate blood, first have a word with the Medical Officer at the donor session.”*

*I would be grateful if you would consider the possibility of including some such advice on these lines.*

16. A handwritten note records the need to report back to Ministers on the usefulness of the pamphlet.

17. Also on 6 March 1984, the meeting of the AIDS and Health Education in Risks Groups discussed the leaflet (among other leaflets) and recommended the following action:

*The leaflet produced by the Department and the National Blood Transfusion Service in 1983 should continue to be distributed through Regional Blood Transfusion Centres – a small revision<sup>1</sup> could be made before reprinting. (WITN5282008-003)*

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<sup>1</sup> There was no detail recorded in the minutes as to the nature of this revision.

18. On 12 March 1984, Mr Green (DHSS) wrote to the Directors of all Transfusion Centres, noting that the AIDS donor leaflet was due for review. He asked for various pieces of information including the current stock levels, the methods of distribution used, any effect on donor attendance and any feedback. He noted that “*We hope to have a draft revision ready before the next meeting of RTDs*” [WITN5282008-001].
19. A minute of a meeting of the SNBTS Directors held on 13 March 1984 [PRSE0003405] records that in Scotland the leaflet had previously been available at donor sessions and at some STD clinics. The Directors felt that their position would be strengthened by mailing it to all blood donors. Dr McClelland had undertaken to revise the existing leaflet and a draft had been circulated with the agenda. It was noted that Dr Smithies was revising the leaflet for England and Wales.
20. On 16 March 1984, Dr Gunson (NBTS Director) wrote to DHSS giving the numbers of current stock and ordered copies of the leaflet in his area, as well as rate of usage in Manchester and Lancaster [DHSC0002239\_045]. He described every donor on the public panel being sent a copy with the call-up card as well as distribution of the leaflets “*to factory sessions prior to the mobile teams visiting the session*”. He said “[a]s far as we are aware there has been no effect on donor attendance”. Further letters from Dr Darnborough of the Cambridge RTCs giving his comments are to be found at [WITN5282008-001].
21. On 28 March 1984, D.S. Fanning wrote to Dr Sibellas enclosing a draft submission with regard to the proposal that the Health Education Council (“HEC”) be asked to draft an AIDS leaflet [DHSC0002309\_039; the submission is at WITN5282008-004], saying:

*I am copying this to Dr Smithies and Mr Winstanley in view of the reference in the draft to the blood donors leaflet. I [...] believe that there was some suggestion that this submission be used as a vehicle for bringing Ministers up to date on where things stand in relation to distribution of the blood donors leaflet (? and possible revision). Perhaps Dr Smithies and/or Mr Winstanley could comment on the submission being used for this purpose (assuming of course, there is anything to report).*

#### April 1984

22. On 10 April 1984, the Advisory Committee of the National Blood Transfusion Service met. Their minutes [WITN5282008-005] recorded:

*“The 6 month trial period of the leaflet “AIDS and how it concerns blood donors” was now complete and the survey of RTDs showed little adverse comment. DHSS now proposed to prepare, in consultation with RTDs, a revised version of the leaflet for submission to Ministers. Dr Rogers suggested that RTDs should adopt a more aggressive approach to discourage donors from high risk-groups from giving blood. The Committee recommended that, although the method of distribution during the trial period had been left to the discretion of RTDs, Ministers should now consider the issue of the revised leaflet with donor call up cards in all Regions.”*

23. On 11 April 1984, Dr Smithies told the Regional Transfusion Directors’ Meeting that a revised and updated leaflet was in preparation [CBLA0001836].

24. On 17 April 1984, R.L. Cunningham noted in a minute to Miss Edwards about the Medical Research Council Working Party on AIDS that the six-month trial of the leaflet had been successful and that the leaflet and the method of distributing were under review [DHSC0002321\_044]. Mr Cunningham also mentioned that Ministers would shortly be asked to consider whether the government should take the lead in arranging for a leaflet about AIDS to be distributed among the homosexual community (such a leaflet was already being drafted by the HEC). A submission was sent by him to Ministers on 17 April 1984 regarding these issues.

25. On 25 April 1984, C.C. Joyce wrote to Miss Edwards saying:

*“Lord Glenarthur has seen your minute of 17 April covering Mr Cunningham’s submission.*

*He takes a somewhat different view to PS(H) – Miss McKessack’s minute of 18 April – in that he favours a further leaflet, directed particularly at promiscuous gays.*

*Lord Glenarthur’s view is based on the fact that there have been criticisms – though not widespread – from correspondents and others that the Department has not done sufficient to increase relevant public awareness. He therefore feels that we should pursue a sensible, non-alarmist course of increased public education.*

*He would like a fuller note on the successful NBTS leaflet trial referred to at para 4 of Mr Cunningham’s submission.*

26. On 26 April 1984, Dr Smithies wrote to Mr Cunningham with comments on the draft submission stating she did not know the plan for submission to Ministers about the HEC leaflet but noted Lord Glenarthur’s comments [DHSC0002321\_045].

May 1984



27. On 9 May 1984, Dr Smithies sent Dr Sibellas and others a copy of the amended leaflet – still called “*AIDS and How it Concerns Blood Donors*” – seeking views [WITN5282008-006]. A handwritten annotation addressed to Mr Williams suggests that someone responded the same day with further amendments.
28. On 16 May 1984, Victoria Brown (Information Division) wrote to Dr Smithies with a suggested amendment moving paragraphs around [DHSC0002243\_006].
29. On 23 May 1984, Mr Cunningham and Miss Edwards sent Dr Smithies their suggested amendments with apologies for the delay caused by a period of leave [DHSC0000178]. Miss Edwards wrote that she intended to put the submission about the HEC initiative on AIDS forward that week. (Presumably she was referring to the draft submission and HEC leaflet described above – see WITN5282008-007 for a June 1984 draft of the leaflet; it was untitled).

#### June 1984

30. On 5 and 7 June 1984, Dr Smithies sent the Regional Transfusion Directors a copy of the new draft of the leaflet seeking comments and amendments from their divisions by 6 July [DHSC0002243\_021, WITN5282008-008 and WITN5282008-009].

#### July 1984

31. On 11 July 1984, the Regional Transfusion Directors’ Meeting recorded that amendments had been sent to Dr Smithies and the draft would be revised [DHSC0002245\_002].
32. On 18 July 1984, Dr Smithies sent a revised draft of the leaflet [WITN5282008-010] along with a draft submission to Ministers [DHSC0002323\_003] to Mr Williams [DHSC0002323\_003]. The submission noted there had been no fall in the numbers of blood donors or adverse comments but there was some discrepancy between distribution methods across the Regional Transfusion Centres. Some sent the leaflet out with recall notifications, some offered them to donors on attendance at a donor session and some just had the leaflet available for donors to pick up. It advocated a “*more positive policy to ensure that donors who may be carrying the transmissible agent for AIDS should be dissuaded from giving blood*” until there could be screening. The submission explained that the redraft was “*to strengthen its warning to high-risk groups not to donate*”. It sought Ministers’ agreement to the issue of the new leaflet and the instruction of RTCs to send out the leaflet individually to their

- registered donors and to ensure new donors had an opportunity to read it. This was amended before being finalised (see final version at **DHSC0002309\_044**).
33. On 23 July 1984, Dr Smithies wrote to Dr Sibellas and others (Miss Evans, Mr Cunningham, Williams, Lister, Brown and Arthur) asking for comments on the redraft and an update on numbers of US cases **[WITN5282008-011]**.
34. On 31 July 1984, Dr Smithies wrote to Mr Williams saying the redrafted leaflet had been cleared by MED IMCD, CHD and ID Divisions and was ready for printing if Ministers agreed **[DHSC0002323\_005]**. There was also reference to the leaflet from the HEC and the screening test for donors being developed.
35. On the same date, Mr Cunningham wrote to Dr Smithies recording their discussion about the diagnostic test but he also noted, “[i]t was for consideration whether the submission [about testing] should also deal with the blood donor leaflet and refer also to the HEC leaflet on AIDS which is in preparation” **[DHSC0000445]**.

#### August 1984

36. On 10 August 1984, Mr Parker sent Mr Joyce Mr Williams’ submission **[DHSC0002309\_044]** seeking agreement to the revised leaflet, still entitled “*AIDS and How it Concerns Blood Donors*” **[DHSC0002309\_044]**. He noted that 1,500,000 leaflets would be required at a cost of approximately £15,000.
37. **Conclusion**. This account of the chronology stops at 10 August 1984, at the point of submission of a revised draft of the AIDS donor leaflet to DHSS Ministers. It does not address further steps taken thereafter.

DHSC Legal Team, July 2021