

# MEETING WITH PHILIP DOLAN, CHAIR OF THE SCOTTISH HAEMOPHILIA FORUM AND COLLEAGUES

TUESDAY 18 MARCH 2008

## Present:

### The Scottish Government

Andrew Macleod  
Sylvia Shearer  
John Brunton

Gillian Russell (SG solicitors)  
Joanna Keating (SG solicitors)

### Haemophilia Representatives

Philip Dolan

GRO-A

Chris James

GRO-A

Frank McGuire (legal representative)

## Introductions

1. Mr Macleod opened proceedings by welcoming Mr Dolan and his colleagues to the meeting and introductions were made.

## Background

2. Mr Macleod then gave a resume of the current position. Matters had moved on since the meeting with the Cabinet Secretary for Health & Wellbeing on 16 August 2007, when she confirmed there would be a Scottish public inquiry. SG officials were now at a critical point following Lord Mackay's Opinion of 11 February 2008, and were working on the details of an inquiry that met the obligations under Article 2 of the Convention of Human rights as set out in Lord Mackay's determination. However, matters were not set in stone and were open for discussion.

3. Ms Sturgeon would make an announcement to the Scottish Parliament on 23 April - subject to parliamentary business - which would include details of the appointment of the chair and the terms of reference of the inquiry. This would be a major milestone for both the Scottish Government and those who had campaigned for an inquiry over a great many years. Mr Macleod stressed that it would be helpful if the meeting's discussions, which should be frank and transparent, were kept private until after that statement was made as the Minister would expect us to do. This was agreed to by all parties present. It was hoped that the statement would give substance to the aims of the inquiry. Mr Dolan made the point that this was a two-sided meeting and Mr McGuire added that he would be pleased to engage with the SG officials present.

4. Mr Macleod went on to explain that there had already been some discussions with Ministers and that Lord Mackay's Opinion raised some important legal and statutory issues that would determine the shape of the inquiry. While Lord Archer's inquiry was still ongoing, this had been overtaken by events and Lord Mackay's judgement had accelerated the process in establishing an inquiry and in putting the practical arrangements in place including the remit.

## **The Inquiry**

5. The inquiry would be held under the Inquiries Act 2005, and would be a compliant inquiry in addressing the two fatalities that were the subject of Lord Mackay's Opinion and in meeting the obligations under section 2 of the Convention. While a fair amount of preparatory work had already been done to set up the inquiry, there was still a lot more to do, although there was a legal framework and some examples to build on. It was thought that the terms of reference would set the scene for a wide ranging inquiry into the circumstances and events of the transmission of Hepatitis C from NHS treatment with blood and blood products. Mr Macleod explained that HIV would also be looked at by the inquiry, as is the case with the Archer inquiry, as it would be most difficult to defend a Hepatitis C only inquiry. A critical step was to identify a suitable chair and Ministers and the Lord Advocate were at present looking at names of senior judges.

6. While the Inquiries Act 2005 provides for an inquiry conducted by a single person or a panel, the proposal was for a chair only, supported by experts. The chair would have a critical and pivotal role in shaping the remit and determining the framework of the inquiry. He/she, together with Ministers, would also have a role in determining the costs and expenses that would be awarded. While the Scottish Government was committed to an effective and efficient inquiry, it was also mindful of costs - the chair would have an important role in this respect. An inquiry under the 2005 Act would be inquisitorial rather than adversarial and would investigate the facts, scrutinizing the large amount of documentary evidence.

7. The Scottish Government would look to release papers as quickly as possible to the inquiry team. There would be a period at the beginning of the inquiry when the inquiry team would concentrate on the scrutiny of the documentary evidence, given that there was a complex set of issues to look at which took place a long time in the past. This would be followed by the oral evidence sessions. Officials were currently looking at strengthening the inquiry team, the physical arrangements including premises, and IT provision.

8. Mr McGuire said that he was not surprised that the inquiry would be held under the Inquiries Act 2005 and that he would also have to look at the expansion of his team and the handling of a great many documents. He made the point that if the qualifications for funding were too tight, this would be restrictive in providing evidence to the inquiry and that this issue would require further discussion. While he did not want to see a "lawyers' bean feast" he said that his team should be well resourced and well equipped, and not be restricted by financial considerations. If the provisions under section 40 (4) of the Inquiries Act were comparable to Stockline, that would make the employment of new staff and the installation of IT equipment etc. to carry out research and cope with the inquiry very difficult. He had a number of issues to cover with each of his clients. Mr Macleod responded by saying that some form of determination would have to be made and that in any event, Stockline was a different set of circumstances. However, Mr McGuire's points would be taken on board for discussion with the chair.

9. Ms Russell then explained that it would be the inquiry team that would do the inquisitorial work as directed by the chair, although it would be helpful if Mr McGuire set out what he thought to be special circumstances, in a factual way, for the Scottish Government to consider, which he agreed to do.

Mr Macleod added that, very early on in the process, the chair would take stock of the issues and key questions that had to be looked at and the levels of funding that would be justified for the parties to the inquiry.

10. Ms Russell then explained that the inquiry would have to be compliant with Article 2 of the Convention and that ministers could not do anything that would cut across that. Mr McGuire made the point that there would be more than two deaths for the inquiry to look at. Mr Macleod said that there would be discussions with the chair to set parameters for the inquiry, which he/she would take forward, although Mr McGuire's views would be made known to the chair.

11. Mr Dolan expressed concerns that discussions with the chair about the remit was a one way process and Mr Macleod explained that the legislation required Ministers to discuss the terms of reference with the chair. He also reminded Mr Dolan that at the meeting in August 2007, Ms Sturgeon had given an undertaking that he and his colleagues would be involved in drawing up the remit, and that it was critical to the inquiry to get this right. He also explained that the 2005 Act allowed for adaptation or changes to the remit as the inquiry progressed and that he was keen to learn Mr Dolan's and his colleagues' views.

12. Ms Russell then explained that an inquiry under the Inquiries Act - section 28 - would look at matters that were wholly or primarily Scottish and the terms of reference would take this into account. Mr Dolan said that he was reasonably comfortable that the inquiry would only relate to Scottish matters, although Whitehall may well hold documents pertaining to Scotland. Ms Russell then explained that the inquiry had to satisfy Lord Mackay's determination. The key paragraph in his Opinion was paragraph 125:

*"any practical and effective investigations of the facts, of the nature required by Article 2, must be capable of addressing when each Mrs [GRO-A] and Mr [GRO-A] became infected with the Hepatitis C virus and whether any steps could have been taken by the SNBTS or by other individuals and public authorities involved in the NHS in Scotland that might have prevented such infection occurring. To restrict any investigations so as to exclude such lines of enquiry would, in my opinion, be incompatible with the provisions of Article 2, whether the requirement for an establish a framework of legal protection or a separate procedural obligation to investigate any death in respect of which Article 2 has been engaged".*

13. The key was to ensure that the remit satisfied the terms of Lord Mackay's judgement. Mr McGuire then said that he was concerned about section 21 and section 28 (4) of the Act, in that restrictions on compelling UK Government officials put in place by section 28 (4) may mean that the inquiry would not be compatible with Article 2 of the Convention, given that the State was the UK authority. Therefore, as an inquiry under the Inquiries Act may not meet the terms of Article 2 and discussions may be needed both legally and politically with the UK Government. Ms Russell acknowledged that the inquiry would have to be article 2 compliant and consideration may need to be given to this issue.

14. Mr [GRO-A] then returned to the funding issue and said that without backing there would not be the prescribed level of support. Ms Russell advised that under the Inquiries Act, Ministers could make expenses determinations with the core participants, capped on a week to week basis. Mr McGuire said that he understood that parameters had to be set, but reiterated that the Stockline model would not work for this inquiry. A three way conversation had to be had between those present at the meeting, the chair and the core group. He

acknowledged, however, that there would not be an open cheque book. He would have to have a conversation with a law accountant.

15. Mr Macleod said that the next matter to consider in preparing for the inquiry was the parliamentary statement by the Cabinet Secretary for Health & Wellbeing on 23 April. Mr Dolan said that he was at present going round the Scotland to speak to haemophilia groups and would be taking views from his parent organisation on the remit. He mentioned that World Haemophilia Day was 17 April and Ms Shearer said that arrangements for the ministerial announcement had yet to be finalised. Mr Dolan wondered why 23 April had been chosen in particular and Mr Macleod explained that now that Lord Mackay had made his determination, Ms Sturgeon was keen to make an early announcement.

16. Mr James asked what form the statement would take and Mr Macleod explained that it would be an oral statement to Parliament, while Ms Russell confirmed that a statement to Parliament was required by the legislation (section 6 of the Inquiries Act). The aim was to keep the terms of reference broad, and to ensure nothing was inadvertently missed out which would curtail the inquiry. Mr Dolan agreed that a broad remit was sensible which would allow all the key issues to be explored. He also said that it was important to have a statement sooner rather than later and that in August 2007, it was assumed that Archer would report in the autumn of that year followed by details of the Scottish inquiry. Mr McGuire then said that he would expect to see the following matters covered by the inquiry:

#### **Blood products: Factor VIII and IX**

- Sources: delivery and distribution (health service network)
- Chronology of knowledge of NonANonB by DH, SNBTS, NHS Trusts/Clinicians
- NHS Trusts/Clinicians distribution of blood products to those suffering Hep C
- When and how were patients told they had Hep C?

#### **Transfusions**

- Source of blood - when was transmission of NonANonB known

#### **Consent:**

- What was the practice of clinicians - did they tell those affected or not?
- What was then done in relation to the distribution chain once it was known to transmit the virus by blood or blood products?

#### **Look back**

- Why only repeat donors?
- Why stop with investigating once people were dead?
- Why only 1995 – 1997 – why stop then?
- What was done regarding tracing patients in general?
- Was there any “drilling down”?
- Was the haemophilia community consulted/involved?
- Patients that were transfused and got Hep C - when were patients told?

#### **Treatment aspect**

- What happened in relation to the development of treatment? (Interferon for example)
- What is the history of this treatment?

## **HIV**

- Development chronology of heat treatment/donor selection/virus inactivation

## **Social Impact**

- Effect on families/incomes/inability to get life insurance/transplant issues
- Side effects of interferon on mental health

## **Secondary Infection**

- What was the knowledge around this?
- What was done to prevent it?

Mr Macleod confirmed that the overall remit should meet the terms of Article 2 and that the broad remit should cover the issues around transmission of Hepatitis C and HIV from NHS treatment with blood and blood products.

## **Social Impact**

17. Mr Dolan then said that the social impact on families that had to live with Hepatitis C/HIV could be great. For instance, it could be difficult to secure a mortgage or get insurance. The consequences could also include cancer and liver disease. He also mentioned the possible mental health affects of pegylated interferon and that several people had died from treatment rather than illness. Mr **GRO-A** concurred that there was sometimes a stigma attached to being a haemophiliac and the haemophilia community was quite private for that reason. He outlined some family experiences. Mr Dolan also said that it might prove difficult for people to give evidence and Mr McGuire added that people must be allowed to tell their stories, which would be an integral part of the inquiry.

18. Ms Russell believed that the chair would be sensitive to the issues and that there could be provision for confidential evidence in terms of the Inquiries Act to be taken if that were necessary. It would be essential that the inquiry secretariat could engage with these witnesses and be sensitive to these issues. Mr Macleod added that social impact matters should be placed before the inquiry, including prognosis and how this affected lives.

## **Conclusion**

19. Ms Russell thought that there was likely to be a quite a long lead in time bearing in mind the experience with other inquiries, maybe six months, before the inquiry would be in position to take oral evidence from witnesses and she could not predict how long the inquiry might last. She asked whether there were any preferences for location and it was assumed that the inquiry would take place in Edinburgh or Glasgow. The venue should, however, be fully accessible for those with restricted mobility.

20. Ms Shearer wondered whether Mr Dolan and his colleagues would be agreeable to a joint press release at the time of Ms Sturgeon's announcement and it was agreed that this was something that merited further consideration. Mr Dolan would consult further before the next meeting.

21. It was agreed by all present that a positive outcome was desired.

### **Action Points**

- **It was agreed that further discussion of the broad terms of reference and individual points would take place.**
- **Mr Dolan suggested that there be a further meeting before the announcement and it was agreed that this would be helpful. It will take place at 2.30 p.m., in St Andrew's House, on Tuesday 15 April.**
- **A note of the meeting would be sent to Mr Dolan and his colleagues by post to remain confidential until after the statement to Parliament.**