



SCOTTISH EXECUTIVE

Deputy First Minister & Cabinet Secretary for Health and Wellbeing
Nicola Sturgeon MSP

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August 2007

Dear Philip

Further to our productive meeting on Thursday 16 August, I enclose a copy of the note taken by my officials, which I trust you will share with your colleagues.

NICOLA STURGEON

**MEETING WITH PHILIP DOLAN, CHAIR OF THE SCOTTISH HAEMOPHILIA FORUM
THURSDAY 16 AUGUST 2007**

Present:

The Scottish Executive

The Cabinet Secretary
for Health & Wellbeing
Derek Feeley
Dr Aileen Keel
Andrew Macleod
John Brunton
Patrick Layden, (OSSE)

Haemophilia Representatives

Philip Dolan
Dave Bissett
GRO-A
Frank McGuire
Chris James
Dan Farthing

1. The Cabinet Secretary welcomed Mr Dolan and his colleagues to the meeting and said that she looked forward to positive engagement. It was agreed that the meeting, as far as possible, should follow Mr Dolan's suggested agenda.

Confirmation that a Public Inquiry will be held in Scotland

2. Mr Dolan said that while he, the Chairman of the Haemophilia Society, and other members, had received correspondence from the Scottish Government that indicated that there would be a Scottish public inquiry following the conclusion of Lord Archer's independent inquiry, there was still some confusion. While the Archer inquiry was relevant, he wanted confirmation that there would, in fact, be a separate Scottish inquiry in due course.

3. The Cabinet Secretary gave Mr Dolan and his colleagues her assurance that she would honour the manifesto commitment to hold a Scottish public inquiry. She, however, believed that the right thing to do was to wait for the outcome of the Archer inquiry, before deciding what still needed to be done in instigating a properly focused Scottish inquiry. At that time there would be further engagement with the Scottish Haemophilia Forum and the Haemophilia Society. Mr McGuire said that this was tremendous news for his clients and mentioned that Mr Farthing had attended every Archer Hearing to date.

Scope and Remit of the Scottish Public Inquiry/Scottish Haemophilia Inquiry Input

4. Mr Dolan made the point that the Archer inquiry was privately funded and that while Lord Archer was a distinguished Chair, his inquiry could not take evidence or cross-examine witnesses. He wondered what the scope of the Scottish inquiry might be. At this point the Cabinet Secretary mentioned that she had read the transcript of Mr Dolan's appearance before the Archer inquiry.

5. There was then a discussion around when the Archer inquiry would conclude: two more sessions were planned for August and a further two to take place after that. The inquiry had carried on longer than originally envisaged and it was agreed that the death of Lord Turnberg's son had probably contributed to this.

6. Mr Dolan wondered about the legal status of the Scottish public inquiry and how it might be funded. He offered to do a paper, although the Cabinet Secretary said that decisions around the statutory and judicial status of the inquiry were for a later date. Mr Dolan was, however, keen that some discussions took place before the end of the year.

7. Mr McGuire then mentioned legal representation and suggested that the way the Canadian (Krever) inquiry had been conducted might offer some useful pointers. There was a risk that an over-elaborate or legalistic approach could be counter-productive. He also mentioned the Irish inquiry, although that had been carried out by a different means, and that anything that could be done to keep the Scottish inquiry focused should be explored.

8. Mr James wondered what the scale of the Scottish inquiry might be and the Cabinet Secretary said that there should be no duplication with the Archer inquiry and that the Scottish inquiry should be focused. Mr Dolan did not believe there had been a great deal of co-operation from the NHS to the Archer Inquiry and that Lord Archer's report might not receive the attention that it merited. The Cabinet Secretary said that such a report would not be ignored and that Scotland had co-operated fully with Archer. Mr Dolan conceded that Professor Ian Franklin, the Scottish National Blood Transfusion Service's Science and Medical Director, had appeared before Archer, although he believed that Professor Franklin had not addressed a number of issues, including the collection of blood from prisoners. Mr McGuire added that it would be important for a Scottish inquiry to listen to Scottish infectees.

Skipton Fund - Pre 2003 Widows

9. Mr Dolan believed that the Executive should re-visit this matter, as the death of a partner had a major impact on the family unit and that the sum of £20,000 would make a difference to the family. The Cabinet Secretary agreed that, in opposition, her party had worked hard to change the terms of the Skipton Fund. However, she explained that to make the changes now would require opening up primary legislation and that, as Mr Dolan was aware, the Skipton fund was a UK-wide Scheme.

10. She was, however, aware that there was a Judicial Review in progress in relation to an individual who had died before the cut-off date of 29 August 2003 and would wait to see the outcome of that. Mr Dolan recognised that the Hepatitis C ex gratia payment scheme was established through the work of the Scottish Executive and mentioned that he did not like the name *Skipton Fund*, as it had no connection with the scheme, but rather the government building it was administered from.

11. Mr McGuire then made reference to the Judicial Review into the decision by the Lord Advocate not to hold a public inquiry into the deaths of individuals who contracted Hepatitis C, and into the decision by Scottish Ministers not to hold a public inquiry into those deaths. He wondered what affect the Cabinet Secretary's confirmation that there would be a Scottish inquiry might have on the JR. The Cabinet Secretary said that the JR raised specific issues on when Ministers were obliged to hold an inquiry. She suspected that the judge would factor her decision into his determination if necessary. Mr Layden made the point that there were two separate matters: the deaths; and the manifesto commitment to hold a public inquiry into why people contracted Hepatitis C from blood and blood products. Mr McGuire would, nonetheless write to OSSE about this matter and the Cabinet Secretary confirmed that he would receive a considered response.

Interferon treatment/Liver Transplants

12. Mr Dolan raised the side effects - mental health problems - that in some cases could be experienced from treatment with pegylated interferon. He also mentioned liver transplants for Hepatitis C sufferers and that there were concerns that as numbers requiring a transplant grew, they were placed further down the waiting list. He hoped this was a rumour rather than a fact. The Cabinet Secretary confirmed that there was no evidence of discrimination; that organs were allocated on clinical priority; there were not enough organs for transplantation; people were waiting longer for organs; and the Scottish Government was placing a lot of emphasis on increasing organ donation.

13. On the question of the side effects of pegylated interferon, Dr Keel explained that most drugs had side effects and that the side effects that could be experienced from interferon (not just pegylated interferon) in a minority of cases were well known. If a patient had depression/suicidal tendencies, this would be taken into account when prescribing interferon. She confirmed that the Chief Scientist would be open to proposals for research into this area if approached. Mr Dolan said that he knew of a number of very able people that had now suffered side effects from interferon treatment and Dr Keel advised that such cases were dealt with as they arose, on an individual basis. With regard to liver transplants, she confirmed that patients were added to the waiting list by clinical priority and that Hepatitis C sufferers were receiving many transplants. She, however, asked Mr Dolan to come back to her should he find firm evidence that this was not the case.

Any Other Business

14. Mr Farthing thanked the Cabinet Secretary for her commitment to hold a public inquiry as the issues distinct to Scotland would not be covered in full by the Archer Inquiry, given its limitations. Mr McGuire also thanked the Cabinet Secretary for her commitment and said that his clients would be delighted to learn of this. Mr [REDACTED] **GRO-A** thanked the Cabinet Secretary for meeting with the Scottish Haemophilia Society so quickly and mentioned that he had been an interferon user and had found it difficult. He said that the issues had crossed various political administrations over a generation and that maintaining public interest in such a complex issue was difficult.

15. Mr Dolan mentioned a meeting that he had had with Malcolm Chisholm around four years ago about the difficulties he and fellow haemophiliacs had in obtaining mortgages and insurance cover, when a representative from the insurance industry was present. This was still an issue and should be re-visited. He asked the Cabinet Secretary to convey the thanks of the Forum and Society to Shona Robison and the Cabinet Secretary undertook to do so. She also confirmed that Ms Robison remained very committed to their concerns.

16. Mr McGuire confirmed that he would write to OSSE and the Cabinet Secretary confirmed that she would wait for the outcome of the Judicial Review on the cut off date for Skipton fund claimants and the conclusion and report of Lord Archer's independent inquiry, before meeting again with the Haemophilia Forum and Society to discuss the nature and scope of the Scottish Public Inquiry.