

# **Minutes of the All-Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood**

20 May 2021

## **Members in Attendance:**

Dame Diana Johnson MP (Labour), Co-Chair, Chairing the meeting

Sir Peter Bottomley MP (Conservative, Co-Chair

Baroness Bottomley (Conservative)

Baroness Campbell of Surbiton (Crossbencher)

Virginia Crosbie MP (Conservative)

Baroness Featherstone (Liberal Democrat)

Nia Griffith MP (Labour)

Ian Lavery MP (Labour)

Baroness Masham (Crossbencher)

Baroness Meacher (Crossbencher)

Andrew Slaughter MP (Labour)

Chris Stephens MP (SNP)

Dr Phillippa Whitford MP (SNP)

Maria Herron, Representing Sharon Hodgson MP (Labour)

Livvy Fox, representing Kevin Foster MP (Conservative)

Joseph Howe, representing Caroline Dinenage MP (Conservative)

## **Speakers**

Penny Mordaunt MP, The Paymaster General

Brian Williams, Special Adviser, Cabinet Office

**Also in Attendance:**

Jeff Courtney, The Haemophilia Society, Secretariat – Minutes

Rebecca Seaford, Office of Diana Johnson MP – Minutes

Richard Angell, The Terrence Higgins Trust

Jessica Bomford, The Haemophilia Society

Jackie Britton, Bloodloss Families

Alan Burgess, The Birchgrove Group

Kate Burt, The Haemophilia Society

Honor Cohen, The Terrence Higgins Trust

Andrew Evans, Tainted Blood

Jason Evans, Factor 8 Campaign

Mary Grindley, Haemophilia Wales

Lynne Kelly, Haemophilia Wales

Adrian Melson, The Birchgrove Group

Karl Monsen-Elvik, Scottish Infected Blood Forum

Maxine Melson, Positive Women

Debra Morgan, The Haemophilia Society

Leila Reid, The Hep C Trust

Aidan Rylatt, The Hep C Trust

Yasmin Samra, Office of the Paymaster General

Clive Smith, Chair, The Haemophilia Society

Sean, Tainted Blood

Susan Stretch, The Hep C Trust

Sue, Tainted Blood

Richard Warwick, Tainted Blood

Glenn Wilkinson, Contaminated Blood Campaign

Clair Walton, Positive Women

# **All Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood**

**Virtual via Zoom - 20 May 2021: 5pm**

## **Agenda**

- Welcome and Introductions
- Approval of the minutes of the last meeting
- AGM of the Group
  - Report on the previous year
  - Election of Officers
  - Income and Expenditure Statement
  - Future Work of the APPG
  - AOB
- Paymaster General, Penny Mordaunt MP will address the APPG on the Infected Blood Inquiry, plans for a compensation framework and the contaminated blood support schemes
- Questions to the Minister
- Close

## **1. Welcome and Introductions**

Diana Johnson welcomed members and guests to the meeting which will be addressed by the minister responsible for the infected blood inquiry Paymaster General Penny Mordaunt MP. The first part of the meeting will be the AGM of the group.

## **2. Approval of the minutes of the last meeting**

Three changes were proposed to the minutes of the last meeting, including correcting the date and time, updating member details for one attendee and correcting the discussion on the MFT trust deed.

**Decision - Members approved the minutes with these changes.**

## **3. AGM of the Group**

### **Report on the previous year**

The APPG's reporting year ends in February and so the latest reporting period is February 2020 to February 2021.

During this period the officers of the APPG wrote to ministers regarding the contaminated blood support schemes seeking improved psychological support and greater parity in support across the UK. Both of these areas have seen improvements this year, but some concerns remain.

I have met with the infected blood inquiry to discuss the progress of the inquiry and we keep the inquiry staff updated on the work of the APPG.

In November 2020 we launched the final report of the APPG's work on access to treatment for people with bleeding disorders. The report made 18 recommendations to Government, the NHS, clinicians and patient groups calling for better access to multi-disciplinary care, parity of support and esteem for women with bleeding disorders and greater patient involvement in decisions about their care.

The report is available on the APPG webpage.

### **Election of Officers**

Following the election in 2019 the group elected 10 officers to lead the APPG. Sir Peter Bottomley and Diana Johnson are the Co-Chairs and there are 7 vice chairs from the SNP, Conservative and Labour parties. We also have Baroness Ritchie as an officer in the House of Lords.

Members were asked if there were any people who wish to become officers of the APPG. The group does not currently have any Liberal Democrats among its officers.

**Decision - The members approved the reappointment of the current officers.**

### **Income and Expenditure Statement**

In the last reporting year, the APPG was provided with support from The Haemophilia Society in researching, writing and publishing the APPG's report. The Haemophilia Society's time and costs

were covered by a grant from Swedish Orphan Biovitrum (SOBI). The value of this support in the reporting year was £9,000.

The Haemophilia Society also provided the secretariat to the APPG and the staff time required for this is valued at £2,750.

The total value of these benefits in kind is below the £12,500 threshold so the APPG does not need to submit an income and expenditure statement for the last reporting year. However, this will be recorded in the register of All-Party Parliamentary groups and in the minutes of the APPG.

#### **Future Work of the APPG**

The future work of the APPG will be discussed at the next meeting. The next AGM of the APPG will take place in Spring 2022 following the end of the reporting year in February 2022.

#### **4. Penny Mordaunt MP addresses the APPG**

Penny Mordaunt welcomed the chance to address the APPG and take questions from members. She noted that she had been keen, ever since she became responsible for these issues, to make progress as soon as possible.

At the time the Written Ministerial Statement was issued she had been able to move forward on a number of issues but said that it had not, in her view, dealt with every issue.

It was important, she said, to bank progress as she did not know how long she would remain in post. That bereaved parents, for example, were not mentioned in the statement was not a reflection that they were seen as less important but instead because they had not been able to propose a solution yet.

She said that progress was being made on parity across the UK and that there would not be any issues on funding for the changes.

Ms Mordaunt updated members on the compensation study. She said it was very important that work began now and was completed before the inquiry concluded. This was not to pre-judge the inquiry but to prevent delays at the end of the inquiry with another piece of work.

They had appointed [Sir Robert Francis QC](#) to lead the study following a search and interview process that she was closely involved with. He was someone they hoped could hold the confidence of the people affected and also had the knowledge and skills to do the work.

Sir Robert is a barrister who has been involved with inquiries into the NHS in the past, has knowledge in medical negligence and is now a non-executive director of the Care Quality Commission and is Chair of Healthwatch England.

His work will start with a brief informal consultation on the terms of reference for the study. The intention is that his work will not overlap with the work of the infected blood inquiry. She understands that there are a very wide range of views on what the framework should look like.

There is a dedicated email address for people to engage with the study, [ibcompframeworkstudy@cabinetoffice.gov.uk](mailto:ibcompframeworkstudy@cabinetoffice.gov.uk)

Ms Mordaunt also provided a brief update on the inquiry which she felt was going well and that they had done a good job to stay on schedule.

She has been working closely with Nadine Dorries MP, who is the health minister responsible for the contaminated blood support schemes, on psychological support.

### **Questions to the Minister**

Baroness Bottomley commented that Sir Robert was a good choice for the role.

Ian Lavery MP asked about the timeline for the study. Ms Mordaunt said that the study will be completed before the end of the inquiry. The initial consultation will last 6 weeks and then the final report of the study will be made before the end of February 2022. Sir Robert will also take a steer from the inquiry when writing his recommendations.

Mr Lavery asked how the affected community will be involved. Ms Mordaunt said that the study will take in the broad range of views of the affected community

Baroness Meacher asked about the current support payments and how they were being increased.

Dr Philippa Whitford MP asked about how the potentially very large amount of compensation will be paid in light of the scandal happening prior to devolution.

Ms Mordaunt said that the work with the devolved administrations on parity had allowed them to have an effective way of working and some underlying principles. The devolved governments are happy to pay their share for the support schemes but compensation will be a separate issue, the levels of payments and the moral obligations will be much more profound.

She said that the support schemes were set up for a particular job and while they were related to the compensation work and Sir Robert would want to consider them, she saw compensation as something different entirely.

Chris Stephens MP asked about engagement with the devolved governments and on how to prevent any delays in the end of the inquiry due to Maxwellisation. Ms Mordaunt said the inquiry was doing as much work as possible in parallel to prevent delays.

Compensation, she said, will address issues that have not been part of the support schemes including bereaved parents and bereaved children.

In reply to a question from Jason Evans from Factor 8 Campaign on whether there will be funding for the affected community to have legal representation to engage with Sir Robert's work, Ms Mordaunt said that she did not expect that to be necessary but that it would be up to Sir Robert.

Diana Johnson asked if the appointment of Sir Robert should have been consulted on. Ms Mordaunt said she felt that that would not have been the best way to choose the study lead.

The Scottish Infected Blood Forum asked whether she could put pressure on the inquiry to provide more time to respond to requests. Ms Mordaunt said that she would take that up.

Baroness Campbell, who spoke of losing her husband due to contaminated blood products, asked about eligibility and access to psychological support. Ms Mordaunt did expect that this would be available to people who were not beneficiaries of the schemes but were still affected.

Diana Johnson asked for an update on the progress towards parity. Ms Mordaunt expected most payments to be made well before the end of the year. She expected increased payments to start being made shortly and for most payments to be made over the summer.

Clive Smith from The Haemophilia Society spoke about the timing of announcements from the Government which always seemed to be made just before a major event and that this was disrespectful. He asked that the Government treat the affected community with more respect and dignity.

Ms Mordaunt said that the intention was not to be discourteous and that she tries to take any opportunities to make announcements as soon as she is able.

In reply to a question in chat from Glenn Wilkinson from Contaminated Blood Campaign, Ms Mordaunt said that without prejudging Sir Robert's review she viewed the current support schemes and the planned compensation framework as something completely different. She does not want people to worry that their current support will be removed.

**Action – The APPG will circulate the contact email for Sir Robert's study**

There is a dedicated email address for people to engage with the study:

[ibcompframeworkstudy@cabinetoffice.gov.uk](mailto:ibcompframeworkstudy@cabinetoffice.gov.uk)