

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

25 May 2016

Members Attending

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

Sir Peter Bottomley MP (Conservative) APPG Co-
Chair

Gareth Russell on behalf of Flick Drummond MP
(Conservative)

Mark Durkan MP (SDLP)

Baroness Walmsley on behalf of Baroness
Featherstone (Lib Dem)

Mary Glendon MP (Labour)

Nia Griffith MP (Labour)

Rt Hon David Hanson MP (Labour)

Kevin Hollinrake MP (Conservative)

Joanne Rolling on behalf of Mike Kane MP
(Labour)

Barbara Keeley MP (Labour)

Stephen Kinnock MP (Labour)

Ed Keyser on behalf of Norman Lamb MP (Lib
Dem)

Chris Matheson MP (Labour)

Jason McCartney MP (Conservative)

Jim McMahon MP (Labour)

Baroness Meacher (Crossbencher)

Jessica Morden MP (Labour)

Jonathan Reynolds MP (Labour/Co-op)

Margaret Ritchie MP (SDLP)

Steve Rotherham MP (Labour)

Andy Slaughter MP (Labour)

Chloe Smith MP (Conservative)

Chris Stephens MP (SNP)

Jo Stevens MP (Labour)

Alison Thewliss MP (SNP)

Anna Gorrell on behalf of Catherine West MP
(Labour)

Craig Williams MP (Conservative)

Nadhim Zahawi MP (Conservative)

Member Apologies

Anne McLaughlin MP (SNP)

Oliver Heald MP (Conservative)

Mark Garnier MP (Conservative)

Baroness Finlay (Crossbencher)

Rt Hon Sir Gerald Kaufman MP (Labour)

Also attending

Jane Ellison, Minister for Public Health

Donna McInnes, Senior Policy Manager, DoH

Kypros Menicou, Policy Lead: Public Health Systems, including TB and BBV Policy, DoH

Kirsty Bell, Senior Private Secretary to the Minister for Public Health

Chris Pond, Chair of the Caxton Fund, invited by the DoH.

Martin Lennon, Researcher and Policy Adviser, Diana Johnson MP

Jeff Courtney, Policy and Public Affairs Manager, The Haemophilia Society – Minutes

Agenda

1. Apologies
2. Re-election of officers
3. Statement on financials
4. Presentation from the Minister
5. Questions and Discussion
6. AOB

Minutes of Proceedings

At the start of the meeting attendees from the DoH did not join the meeting while the formal part of the AGM was conducted.

1. Apologies

The Chair read out the list of apologies above.

2. Election of officers

Diana Johnson MP and Sir Peter Bottomley MP had indicated their willingness to restand as Co-Chairs prior to the meeting.

Decision – Diana Johnson MP and Sir Peter Bottomley MP were appointed Co-Chairs for 2016-17

Huw-Irranca Davies has stood down as vice-chair following his resignation from parliament. Current officers Chloe Smith MP, Kevin Hollinrake MP, Jessica Morden MP and Barbara Keeley MP had indicated their willingness to restand as vice-chairs. Andrew Slaughter MP, Chris Stephens MP and Margaret Ritchie MP had indicated their willingness to stand as vice-chairs.

Decision - Chloe Smith MP, Kevin Hollinrake MP, Jessica Morden MP, Barbara Keeley MP, Andrew Slaughter MP, Chris Stephens MP and Margaret Ritchie MP were appointed Vice-Chairs for 2016-17

Action – Update the APPG Register with the new officers

3. Statement on Financials

The chair confirmed that the total gifts in money or in kind received by the group in 2015-16 was less than £12,500 and therefore there was no requirement to produce an income and expenditure statement.

The chair informed the group that the Haemophilia Society continue to provide the group's secretariat and that this gift in kind is valued in the £1,500-£3,000 bracket.

Action – Update the APPG Register to the current benefits in kind

4. Presentation from the Minister

At this point in the meeting the Health Minister and the DoH civil servants re-joined the meeting. The Minister and Donna McInnes gave a presentation on the planned reforms and updated the group on the status of the consultation on reform of the support schemes for people affected by contaminated blood.

The slides delivered included:

- Background on the existing schemes
- Expected spend per year on support from 2014-15 to 2020-21
- How current support is split between different types of support
- A breakdown by disease of individuals registered with the current schemes
- A graph showing a comparison between proposed English support and the Scottish proposals
- An overview of the respondents to the consultation

There had been an open consultation and the Department was listening to the responses. Figures were provided to show that spending on support will double under the new scheme however the new budget as allocated will not be changed. The new scheme had to be legal.

The focus of the reforms has been on people with Stage 1 Hepatitis C because they are the largest group but get no annual payments. The minister noted the range of illness within what is currently defined as Stage 1.

An example was provided of a person with stage 1 Hepatitis C who if entitled to the maximum £15,000 per year payment would be better off than under the current scheme and the Scottish proposals. The minister stated there should be no one who is worse off under the new scheme.

Commenting on the consultation responses, all of which have been analysed, the minister noted the areas in which they are reconsidering the proposals. Discretionary payments should cover a wider range of things than currently proposed. Only 4% of respondents supported the health-based assessments so these would be reconsidered. The removal of the link to CPI was also opposed and this will be looked at.

Most respondents supported the simplification of the schemes and wanted a single point of contact.

5. Questions and Discussion

Questions were asked by the APPG members, some of which were answered by the minister and the civil servants present. On some other issues the Minister promised to write to the APPG.

Q – On the appropriateness of the liable party setting the support arrangements

No reply

Q – On the consultation response form and the inability for co-infected individuals to identify themselves as such and on the impression that money was being reallocated from the co-infected community to the Stage 1 Hep C community.

The minister had not seen a letter from the APPG member. The money assigned to support was being increased. There were discretionary payments that they did not know about at the time of producing the proposals. Some discretionary payments had become regular.

Since the launch of the consultation the DoH has become aware of discretionary payments that were not considered in the new proposals and she intends to respond to them.

Q – On the consultation's relevance to people in Wales and Northern Ireland

The consultation's proposals are for people infected in England but DoH civil servants have been talking to their counterparts in Northern Ireland and Wales. The DoH expect this issue to get more ministerial attention in Wales and Northern Ireland now that the elections are over.

Wales and Northern Ireland can propose and implement their own scheme as has happened in Scotland or they can follow the English Scheme. The extra money announced is for England only and there will not be Barnett consequentials. Funding for the schemes in Northern Ireland and Wales will come from their Health budgets.

Q – On the proposals to use funds allocated to support to fund access to Hepatitis C treatment

The minister noted that she had received and responded to a letter from Diana Johnson on Hepatitis C drugs. The minister had taken on board that money allocated for support should only be spent on support.

Q – On whether devolution of Health responsibility to Manchester would allow them to introduce their own scheme

The minister believed it was not possible but would write to the MP. There was concern that this would create challenges in relation to determining the place of infection.

Q – On the reallocation of support from one affected group to another

The minister restated that no one will lose out as result of lower annual payments.

Q – On the proposed health-based assessments

The Government are reflecting on the proposals for assessments

Q – On Wales and Northern Ireland

The minister will talk to ministers in Wales and Northern Ireland.

Q – On what account the department has taken for the rate of death among scheme beneficiaries

This is not something the department has considered when setting the funding for the scheme.

Q – On support available for dependents and widows of people who die or are deceased

The department is aware of this issue. The new system will be flexible and the discretionary funding will include a principle to support people in this situation.

Q – On the scrapping of the existing trusts

There are legal and commercial issues relating to scrapping the trusts.

Q – On the timeline for implementing the changes

All payments will be backdated to April 2016. The Minister aims to have new schemes will be in place for the start of the next financial year in April 2017.

Q – On the timings of the response to the consultation, the Minister was pushed to respond as quickly as possible and preferably before the Summer Parliamentary recess.

While they wish to respond as soon as possible, the government cannot commit to responding before summer recess.

At the end of the meeting the Chair thanked the Minister for attending the meeting. The Minister committed to responding in writing to points which were not addressed during the meeting. This will be included with the response to the letter from Diana Johnson MP and published on the APPG webpage.