

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

13 April 2021

Members in Attendance:

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

Andrew Slaughter MP (Labour)

Ian Lavery MP (Labour)

Catherine West MP (Labour)

Kirsty McCafferty (representing Alison Thewlis MP (SNP))

Jenny Symmons (representing Janet Daby MP (Labour))

Livvy Fox (representing Kevin Foster MP (Conservative))

Dan Parker (representing Jessica Morden MP (Labour))

Representative of Caroline Dinenage MP (Conservative)

Representative of Stuart C McDonald MP (SNP)

Also in Attendance:

Jeff Courtney, The Haemophilia Society, Secretariat – Minutes

Rebecca Seaford, Office of Diana Johnson MP - Minutes

Richard Angell, The Terrence Higgins Trust

Honor Cohen, The Terrence Higgins Trust

Debra Morgan, The Haemophilia Society

Aidan Rylatt, The Hep C Trust

Clive Smith, Chair, The Haemophilia Society

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

Virtual via Zoom - 13 April 2021: 2pm

Agenda

- Welcome and Introductions
- Changes to the Contaminated Blood Support Schemes
- A Compensation Framework
- Next Steps and Actions for the APPG
- Next Meeting and any other Business

1. Welcome and Introductions

Diana Johnson welcomed members to the meeting which was called to allow members to discuss the announcement on changes to contaminated blood support and plans for a compensation framework that was made before recess. [The full announcement is available here.](#)

She announced that the minister responsible Penny Mordaunt MP would address the next meeting of the APPG which is scheduled for **Thursday May 20th at 5pm and will take place virtually via Zoom.**

2. Changes to the Contaminated Blood Support Schemes

Jeff Courtney from The Haemophilia Society updated members on the latest announcement. The announcement said that “broad parity” will be achieved for all beneficiaries across the UK. There will continue to be 4 schemes, one in each part of the UK, but they will become broadly aligned and in future any changes should be discussed by the four governments.

We know that the new payments will be backdated to April 2019, will apply to current registrants of the schemes and the new payments or increases in payments will be made by the end of 2021.

The main changes are that:

- Bereaved partners will receive an automatic £10,000 lump sum plus 100% of their partner's annual payment for one year followed by 75% of the payments their partner was receiving going forward.
- The lump sum payment paid to Hep C stage one beneficiaries will increase to £50,000, in line with current payments Scotland
- The lump sum paid to a beneficiary with HIV will increase to an automatic £80,500
- Most annual payments for primary beneficiaries across the UK will be uplifted in line with those paid in England

However, this raises some issues and unknowns such as:

- How far back the Government will go in matching lump sum payments and ensuring those eligible are able to apply for them?
- Will new or increased lump sum payments be available to the surviving next of kin or the estates of those who have died?
- Will the amounts paid as lump sum payments be adjusted for inflation to make up for the time passed since originally eligible beneficiaries received the payments?
- How will remaining differences between the four schemes be dealt with?
- What support will be available to people infected with viruses not covered by the schemes such as Hep B, D and E?
- Why have people who naturally cleared hep C or were otherwise lacking in medical evidence still not been able to join the schemes?
- What support will be available to bereaved parents and children?
- How will the increase in psychological support be provided?
- How will the government seek to promote the schemes to those not registered?

The Haemophilia Society have drafted a [quick guide to the contents of the statement and what it means for their members.](#)

Some, mostly minor, variations remain across the schemes and other annual payments may look different due to the way they are constituted. For example Scotland includes the winter fuel

component in the main amount rather than paying this separately and Northern Ireland continues to not have Hep C impact adjustments.

The Haemophilia Society have compiled a comparison table that illustrates the new payments.

Catherine West MP asked about the extent to which discretionary or means-tested payments remained. Jeff confirmed that the main annual payments were not means-tested and available to all eligible beneficiaries, however the discretionary parts of the schemes were expected to still remain if people needed them.

Ian Lavery MP asked why bereaved parents and children were excluded from the schemes. Clive Smith noted that the schemes were created 30 years ago and were not originally envisaged to last this long. Honor Cohen explained that the original MFT Trust deeds did include parents and children of people infected with HIV but in later years this was not how MFT had worked.

Diana Johnson suggested that this should be something the APPG raises with Government.

The extent to which all encompassing changes should be included in the support schemes or whether the compensation framework should be the vehicle for this was raised.

Action – The APPG will formally write to Penny Mordaunt MP outlining the remaining concerns and issues.

Ian Lavery noted that it may be important to raise concerns now, so they are not ignored later.

Catherine West suggested that the APPG should have an agreed line and statement on the announcement to help members answer queries from constituents. Members agreed that the APPG should list what anomalies exist and where further clarity is required.

Action – The Secretariat will draft a position statement for the APPG to agree.

3. A Compensation Framework

Jeff Courtney updated members on how the announcement included plans for the government to appoint a person to lead a study into creating a framework for compensation. Little detail is as yet available on this process. Instead a number of issues members may wish to raise include:

- When will the independent reviewer for the compensation framework be appointed?
- How will it be ensured that the independent reviewer is fully independent of Government?
- How will the independent reviewer ensure all affected individuals can contribute effectively to the study?
- What is the timeline for the independent reviewer's study? When can we expect it to report?
- In addition to Ireland, what other countries' frameworks will the reviewer seek to consider?
- Is the intention to create a framework that creates broad categories of people affected or is the intention that individual settlements will be made?
- What commitment will the Government make to implement the compensation framework?

- By beginning this process towards a compensation framework is the Government now willing to admit liability for the contaminated blood scandal? What does this statement and process mean for liability?

Clive Smith added that a number of different people may be appropriate for the role. It could be that another high court judge leads the process

Andrew Slaughter asked how these announcements link to the work of the inquiry.

Clive Smith explained that the inquiry plans to report in Autumn 2022 but that it will only make recommendations which it will be up to the Government to implement. However, it would be surprising if the recommendations did not include compensation. There is a case that the inquiry will recommend that punitive damages are made, in light of the cover-up.

The lead for this study may need a medical as well as a legal background, he added.

Diana Johnson asked whether members had any ideas on who should lead the review. The Government was open to suggestions on the most appropriate person.

Andy Slaughter asked if this announcement had come as a surprise. Clive Smith said that it was a big surprise to get an announcement to this extent. Also, this was a poignant moment for the community as it was the first time the government has openly considered compensation.

Richard Angell added that it was a big deal that the word compensation was used. However, conversations with the Treasury are continuing. It was interesting that the Government's language seems more similar to that used in Ireland rather than New Zealand for their compensation schemes.

Debra Morgan added that the inquiry had stated that they were very keen to work with the appointed person.

4. Future Next Steps and Actions for the APPG

Diana Johnson suggested that once the inquiry is complete work could be done to understand why this inquiry and chair has been able to maintain the trust of the affected community. Are there lessons that should be learned for other inquiries in future. The APPG may consider some work on this.

Andy Slaughter contrasted this with the Grenfell inquiry which has faced more difficulties.

Clive Smith noted the work of academics at Nottingham University on public inquiries. In the longer term the Government may wish to have a permanent inquiries unit so that a new system doesn't have to be created fresh for every inquiry.

5. Next meeting and Any Other Business

The next meeting of the APPG will be on **Thursday May 20th at 5pm for the group's AGM** followed by a meeting with Paymaster General and Minister responsible for the public inquiry Penny Mordaunt MP who will talk about the latest announcement and take questions from members.

The APPG should consider having an online presence beyond the webpage. Perhaps in the form of a twitter account.

Action – The Secretariat will investigate setting up a Twitter account