

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

9 May 2018

Member Attendance:

Diana Johnson MP, Co-Chair, Chairing the meeting

Sir Peter Bottomley MP, Co-Chair, Conservative)

Kevin Foster MP (Conservative)

Stephan Kinnock MP (Labour)

Jim McMahon MP (Labour)

Andy Slaughter MP (Labour)

Nick Taylor, representing Caroline Dinenage MP (Conservative)

Stella Tsantekidou, representing Anna McMorrin MP (Labour)

Catherine West MP (Labour)

Apologies:

Baroness Findlay of Landaff (Crossbench)

Kevin Hollinrake, MP (Conservative)

Also in Attendance:

Ginny Belson, Department of Health and Social Care

Jeff Courtney, Head of Policy and Public Affairs, The Haemophilia Society, Secretariat - Minutes

Jasmine Cracknell, Parliamentary Assistant, Diana Johnson MP

Anne Hildyard

Georgina Johnson, Department of Health and Social Care

Lynne Kelly, Chair, Haemophilia Wales

Jennifer Martin, Hanover Communications

Donna McInnes, Department of Health and Social Care

Claire Poynton, Policy and Public Affairs Assistant, The Haemophilia Society

Aidan Rylatt, Policy and Parliamentary Advisor, The Hepatitis C Trust

Della Ryness-Hirsch

Nicholas Sainsbury, Tainted Blood Reformed

Clair Walton, Positive Women

Barry Ward

Glenn Wilkinson, Contaminated Blood Campaign (CBC)

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

Room A, 1 Parliament Street - 9 May 2018: 4pm

Agenda

- 1. Welcome and Introductions**
- 2. Update from the BSA on the SCM and other developments**
- 3. Update from Jackie-Doyle Price on the Overall Scheme**
- 4. General Questions on support provided (payment levels etc.)**
- 5. Questions on the SCM**
- 6. Questions on Bereaved and Discretionary Support**
- 7. Any other questions**

1. Welcome and Introductions

The Chair welcomed members and guests to the APPG meeting. The APPG was addressed by Health Minister Jackie Doyle-Price. She was joined by Chris Tempest and Chris Calise from the NHS Business Services Authority (BSA), the Government body that runs The England Infected Blood Support Scheme (EIBSS).

2. Update from the BSA on the SCM and other developments

The BSA said they had taken over administration of the support scheme for people affected by contaminated blood and blood products in England (now known as EIBSS) in November 2017.

Mr Tempest was responsible for the services and support provided by the BSA through EIBSS. Chris Calise had overall responsibility for Patient Services at the BSA.

They updated members on the BSA's commitment to engaging with the public and meeting groups of beneficiaries of the scheme. He noted that the BSA have now completed their review of discretionary support provision.

It was said that more meetings will be held soon in different locations to better understand the needs of beneficiaries and to improve the overall scheme.

Turning to the Special Category Mechanism (SCM), as of April 26th, 700 applications had been received, of which 77% have been successful. More applications were expected by the May 14th deadline, but the scheme remained open for people to apply in future. Successful future applications would have payments backdated to the date the application was received.

The BSA were committed to providing continuity of payments via the SCM and would continue to meet with beneficiaries and encourage participation. They were focussed on providing clear information particularly around the changes to discretionary payments.

3. Update from Jackie Doyle-Price on the overall scheme

The Minister noted that efforts were being taken to be responsive to the needs of beneficiaries and provided a guarantee that no one will be out of pocket by the new scheme. The new discretionary support scheme would level up payments to the most generous support under the previous scheme.

4. General Questions on support provided (payment levels etc.)

It was asked whether guidelines had been sent to all those that are eligible to apply for support, and whether these guidelines provided information about what support was being offered.

The BSA have reviewed the information that was already available and were currently updating it. Clear guidance would be made available on the BSA website in the near future, which should be by the end of the month.

A question was asked when the community will know what they can and can't apply for, and why three months of bank statements were required for support applications.

The BSA responded that the discretionary payment schemes and the required paperwork were currently under review. The request for 3 months of bank statements was to verify income. It was said that this requirement would be reviewed, and it was acknowledged by the minister that this was an intrusive requirement.

Co-Chair Peter Bottomley MP raised concerns about Personal Independence Payment (PIP) assessors who were not experienced in haemophilia and complications related to viruses acquired through contaminated blood and blood products, suggesting that people should be 'starred' by the Health Service so that they did not have to go through the same processes multiple times.

The chair said that the DHSC and DWP were not keen on 'pass-porting' people through the system, but that better use of data sharing was needed.

A question was asked about the availability of white goods on the new support scheme, and whether past support would be continued by new schemes. Mr Tempest said that he would follow up with this individually.

Concerns were raised about the lack of representation for women with HIV, noting that there had been no meetings that they had been able to attend.

Mr Tempest said that the BSA aimed to have a reasonable number of people at each meeting and have thus far not been able to meet everyone they wanted to. It was said that at least one more meeting would be held by the end of May.

It was asked how people were kept informed about the new scheme. This depended on individual preferences.

It was asked when the next SCM appeal would be, and why this scheme was implemented to start with. It was said that communications about the next appeal would be sent out in the next two weeks. This scheme was implemented following consultation with beneficiaries and took into account the Judicial Review. The Minister accepted that not everyone was happy with the changes.

In reply to a question on Macfarlane Trust loans and charges, and whether there had been any discussions regarding this, it was said that the plan had been to transfer the loans to an appropriate charity but no conversations had taken place on actioning this.

The Minister noted that some loans may have been signed inappropriately and would consider this.

The Minister said that she was writing to the Macfarlane Trust to deal with outstanding issues regarding loans and any residue of money.

The Minister said that it was important the Macfarlane Trust was wound up. She intended to write to the trustees brusquely to push forward outstanding actions.

A question was asked regarding the legacies from the Macfarlane Trust. The Minister said that no money would be lost.

It was asked whether the names of trustee members of the Macfarlane Trust will be made available. It was said that this information should be available on their website.

The Haemophilia Society said that it would find this information and put it in the minutes.

[The current trustees are listed here: <http://beta.charitycommission.gov.uk/charity-details/?regid=298863&subid=0>]

A question was asked regarding the legacies of the Skipton Fund and Caxton Foundation and whether residual money will be delivered to the BSA and not returned to the government. Jackie Doyle-Price said that there little remaining reserves, and no legacies.

The Minister promised to provide clear answers on this.

It was asked why reserves left from the Macfarlane Trust had not been transferred over to the new schemes. It was said that any money held by the trust should be spent before it is wound up. Any surplus will go to an appropriate charity. It was expected that the Macfarlane Trust would be the last to be wound up and that this would take place in 2019.

Issues were raised regarding the Scottish scheme, and whether it is more generous than the English scheme. It was noted that the schemes work differently for different people, and that it depends on individual circumstances.

It was noted that everyone in the community needed to be included in the development of payments schemes, and that the current schemes had become too complex.

In reply to a question on why the Government was not apologising and paying victims compensation, the chair said that this may be an outcome of the public inquiry.

5. Questions on Bereaved and Discretionary Support

It was asked whether the minister could provide assurance that all widows will be treated the same, regardless of what their partner died of.

In response to further questions on the support available to bereaved partners, the minister said that there will be no losers in the new scheme and all people supported will have their entitlements raised to the same level as the best entitlements previously available.

A question was asked regarding the availability of support for widows of previous marriages in which the couple had children, and the spouse later remarried. A further question asked about carers. Jackie Doyle-Price noted that it is important to consider dependents in addition to widows.

7. Any other Questions

A question was asked regarding the disregarding of EIBSS payments for access to benefits noting that currently the DWP was disregarding income but not savings. The BSA replied that this was not correct, and they were working with DWP to reissue guidance.

A question was asked regarding the availability of financial support whilst the inquiry is ongoing. The Minister noted that this was outside of her responsibilities.

A question was asked about the long-term nature of the scheme, when a replacement scheme would be developed and what assurances she could give beneficiaries. The Minister noted that the focus was on the current scheme, and that more focus would be paid to new scheme as this one finishes.

A question was asked as to whether people from the Macfarlane Trust now worked for the new scheme administrators. It was said that some staff do now work in for the BSA.

The BSA added that they were keen to be informed of any issues beneficiaries had with staff.

Concerns were raised over the minutes provided for the last APPG meeting. It was noted that the minutes represented the APPG's views on the public inquiry and the use of the panel but this conversation had not occurred as recorded. The chair noted that it was not within the remit of the APPG to determine whether Judge Langstaff will carry out the inquiry alone or with a panel, but that this was the preferable option. The Secretariat said they will amend the previous minutes to remove this section.

A question was asked of the Chair if an audio recording of the meeting had taken place. The Chair said that they had not been made aware that a recording had been taken. It appeared that a recording had been taken of the meeting.

Finally, it was noted that a date will be set for the summer AGM meeting.