

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

31 January 2018

Members Attending

Sir Peter Bottomley MP (Conservative) – Co-Chair, Chairing the meeting

Baroness Meacher (Crossbencher)

Andy Slaughter MP (Labour)

Chris Stephens MP (SNP)

Alison Thewlis MP (SNP)

Dan Parker, representing Jessica Morden MP (Labour)

Also in attendance

Tom Stephens, Parliamentary Researcher, Diana Johnson MP

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

NB, Birchgrove Group

Jackie Britton, Founder, Bloodloss Families

Lesley Brownlees, Contaminated Blood Women

Liz Carroll, Chief Executive, The Haemophilia Society

Des Collins, Solicitor, Collins Solicitors

Debra Morgan, Public Inquiry Lead, The Haemophilia Society

Christopher Munn

Barnaby O'Connor, Contaminated Whole Blood UK

Glenn Wilkinson, Founding Member, Contaminated Blood Campaign

Matthew Bold, representing Jo Stevens MP (Labour)

Kevin Garvey, representing Jim McMahon MP (Labour)

Member Apologies

Dr Philippa Whitford MP – Vice-Chair

Diana Johnson MP – Co-Chair

Paul Desmond, CEO, thetruthabouthepc.org

Andrew Evans, TaintedBlood

Jason Evans, Factor 8 Campaign

Stephen Finney

Mary Grindley

Anne Hildyard

Gemma Holding

Dani Holliday, Solicitor, Collins Solicitors

Lynne Kelly, Chair, Haemophilia Wales

Della Ryness-Hirsch

Nick Sainsbury, Founding Member, Tainted Blood Reformed

Clair Walton, Positive Women

Tim Wratten, The Fatherless Generation

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

Room A, 1 Parliament Street - 31 January 2018: 4pm

Agenda

- 1. Introductions and Apologies**
- 2. Minutes of last meeting**
- 3. Update on the Inquiry and Monday's UQ**
- 4. Update on the Support Schemes**
 - Update on the Special Category Mechanism
 - The Business Service Authority's planned review of discretionary support.
 - Use of Macfarlane Trust reserves – response from the minister
- 5. ESA and PIP support for those affected by the Scandal**
 - DWP Working Group meetings
 - PIP Forum for those affected by the scandal.
 - Planned meeting with Disabilities Minister Sarah Newton MP
 - Welfare support from the BSA
- 6. Any Other Business**

1. Introductions and Apologies

The Chair welcomed members and guests to the APPG meeting.

The Chair asked that groups working on the inquiry ensure the chairs of the APPG are kept updated.

2. Minutes of last meeting

The Chair invited questions regarding the minutes of the previous meeting. No questions were raised.

Action - The minutes of the last meeting will be made available on the APPG webpage and circulated by email.

3. Update on the Inquiry and Monday's UQ

Tom Stephens updated members on developments towards the creation of the statutory inquiry into contaminated blood and blood products.

An urgent question took place on Monday, led by APPG Co-Chair Diana Johnson. In response a minister said that an announcement of the chair would happen very shortly. The expectation remains that an appointment could be made within days or at most weeks.

It was noted that delays in the appointment of the chair may be due to staff and ministerial moves within the Cabinet Office. Since the last APPG meeting, Cabinet Office Minister Damian Green has been replaced with David Lidington and it is understood that senior civil servant Sue Gray is going to move to take up a position in Northern Ireland.

A question was asked on whether the chair of the inquiry would be working full time on the inquiry. This was said to be the expectation.

The UQ also included confirmation that the intention was that the inquiry would not only include the events leading up to the scandal but also the aftermath.

It is expected that following appointment of the chair an engagement process will be created to allow victim groups to feed in to the terms of reference.

4. Update on the Support Schemes

a. Update on the Special Category Mechanism (SCM)

Jeff Courtney updated members on the SCM. Applications received so far are being processed and the results of the first round of applications will be made and sent to applicants in mid-February, with the first payments made in March 2018, backdated to October 2017.

The SCM remains an open scheme and people who have not yet applied can start an application at any time, unsuccessful applicants can appeal their decision or start a new application after 6 months if their situation has changed or they have new evidence.

So far it seems that application rates have been lower than expected.

Those present at the meeting raised continuing concerns over the application process and that there is a lack of attention paid to the extra-hepatic manifestations of Hepatitis C. Some campaigners continue to call for a full scrapping of the Stage 1/Stage 2 distinction.

More work is still required to work out how to support those who are not successful through the SCM, or not eligible to apply but still need additional support.

The SCM does not take into account historic suffering or loss it is aimed at providing financial support to those who still have ongoing health issues as a result of their Hepatitis C or its treatment.

b. The Business Service Authority's planned review of discretionary support.

Following meetings with the BSA Jeff Courtney updated members on the engagement and review of the discretionary support scheme in England. A survey has been sent to beneficiaries to get their input on how best to provide discretionary support from April 2018 onwards and other aspects of the scheme. However, they are seeking input from beneficiaries as to the best way to provide the support. Members were suggested to encourage beneficiaries to engage with the scheme administrator to ensure their views are heard.

The scheme intends to ensure no one is worse off following the changes to discretionary support. The existing discretionary payments and arrangements will remain in place until a new scheme is in place. It is likely now that no changes to the discretionary support scheme will take place until July 2018.

Ongoing concerns with the discretionary aspects of the scheme were raised by those present. It is expected that the new scheme will continue to rely on means-testing to allocate a restricted budget.

It was suggested that discretionary support represented tinkering and ad-hoc improvements to the support scheme which could be better and more easily dealt with through increases to the guaranteed annual payments. It was questioned whether the costs of administering a system of grants and top up payments was justified and efficient. The Chair suggested that the Government needs to understand the costs associated with friction in the system.

It was asked if the BSA could make the process for receiving Prescription Prepayment Certificates easier. They are provided free of charge to all beneficiaries who request them but are not sent automatically.

Members asked for further information on the current nature of the support schemes and areas where support is still lacking.

Broader concerns were also raised about the basis of the ex gratia support scheme – which all agree is wholly insufficient to meet the needs of those affected by the disaster – and the best way of campaigning for improvements in support. Tom Stephens reiterated that everyone is agreed that the support is wholly insufficient, and that even calling the support “ex gratia” wrongly implied there was no liability.

Action – The Secretariat will produce a more detailed review of the support available to people affected by contaminated blood once the current changes are complete.

c. Use of Macfarlane Trust reserves – response from the minister

Tom Stephens updated members on the new MfT process to spend its remaining reserves. The MfT has invited beneficiaries to apply for grants for home adaptations.

There were concerns raised that the new grants were not capturing the full needs of its beneficiaries. It was observed that this process was working in a similar way to the previous work of the MfT which has been criticised in the past.

The Under-Secretary of State for Health, Jackie Doyle-Price MP, has confirmed that the Eileen Trust and Caxton Foundation do not have reserves, so no such exercise is being carried out by them.

In response to a question, it was confirmed that issues related to loans and charges made by the MFT to its beneficiaries had not yet been resolved.

Action – Tom Stephens agreed to raise the point of loans and charges again with the office of the Under-Secretary of State for Health. This had originally been raised by Nadhim Zahawi MP and the Minister had promised, both in writing and verbally, to personally look into this.

5. ESA and PIP support for those affected by the Scandal

- a. DWP Working Group meetings
- b. PIP Forum for those affected by the scandal.

Tom Stephens updated members on the DWP working group of people affected by contaminated blood and blood products. The working group had now met twice, and their latest meeting took place earlier on 31st January 2018.

The members of the group had pushed for automatic passporting to PIP and ESA for certain beneficiaries of the contaminated blood support schemes. It was also sought that they could be removed from the processes of reassessment.

While there is sympathy within the DWP, it was observed that these changes would require primary legislation and that therefore they were unlikely to be taken up

Action 2 – Tom will circulate a note of the meeting round to the APPG. It will also provide more precise details on why the Government claims it would require legislative change to allow for passporting, and what form this legislative change would take.

More promising was consideration by the Joint Health and Work group on better use of data and information provided to DWP assessors and the support scheme administrators. For example, the potential of information provided to the SCM process being made available to PIP assessors.

There are also wider problems with the WCA and PIP assessments for people with multiple conditions, fluctuating condition and mental health issues.

The possibility of the Work and Pensions Select Committee having a short inquiry or one-off evidence session on the experiences of people affected by the contaminated blood scandal was discussed.

Action 2 - The Chairs will write to Frank Field MP suggesting an inquiry.

Those present raised the issue of beneficiaries being called to have interviews under caution. Instances where the capital disregard was not working were also mentioned. The BSA in England are able to step in to ensure payments from the support scheme are disregarded for benefits or tax however not everyone is receiving this assistance and in some people are not willing to disclose their payments.

A question was asked raising concerns that people living with or successfully treated for Hepatitis C were being turned down for benefits due to a lack of understanding of the range of impacts.

In addition, in the working group meeting, the DWP identified there may be issues with how the welfare re-assessment system considers those with bleeding disorders. They are looking at changing the guidance on this, but asked whether someone would be able to advise on a doctor who might be able to look at their updated guidance free of charge.

Action 3 – Tom will advise the DWP that the Haemophilia Society is happy to be consulted if they need a doctor to look at the descriptors and the conditions for those with bleeding disorders.

Finally, the APPG Co-Chair will be meeting with the Disabilities Minister, Sarah Newton MP, to discuss welfare support and passporting. An update on this meeting will be provided once it takes place

c. Welfare support from the BSA

Anyone under the English scheme who needs welfare rights advice can now get it through the Business Services Authority (BSA). The BSA can recommend a benefits advisor and will cover the costs of their time. Any individual can get this assistance by calling 0300 330 1294 or emailing nhsbsa.eibss@nhs.net.

They are also working on providing counselling for people who are not getting the support they need through the NHS. People who would benefit from this should also contact the BSA.

It was suggested that beneficiaries should be able to source their own benefits advisor and for this to be funded by the BSA.

Action – The Secretariat will raise this question with the BSA and report back.

6. Any Other Business

Concerns were raised about the process of selection of the chair of the statutory public inquiry and the consultation on the terms of reference. It was suggested that too few non-bleeding disorder campaign groups were consulted and the written submissions considered were those sent to the DH which was boycotted by some groups and individuals.

A question was asked regarding the Honeycombe Legacy held by the Macfarlane Trust. The APPG has written to minister but so far no useful information has been provided by the MfT. It was discussed that any remaining funds in the Legacy must legally be used for the charitable aims.

Action – Diana Johnson MP and her office to raise the Honeycombe Legacy with the Minister and establish what will be happening to these funds, and reiterate that the Legacy funds must be used for their specific charitable aims.