

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

29 March 2017

Members Attending

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

Baroness Meacher (Crossbencher)

Andy Slaughter (Labour) – Vice Chair

Nadhim Zahawi MP (Conservative)

Member Apologies

Mark Durkan MP (SDLP)

Alberto Costa MP (Conservative)

Alistair Burt MP (Conservative)

Alison Thewlis MP (SNP)

Stephen Kinnock MP (Labour)

Baroness Finlay (Crossbencher)

Barbara Keeley MP (Labour)

Frank Field MP (Labour)

Also attending

Tom Stephens, Parliamentary Researcher, Diana Johnson MP

Liz Carroll, Chief Executive, The Haemophilia Society, Secretariat

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

Daniel Tye, Office of Sharon Hodgson MP

Jessica Prestidge, Office of Caroline Dinéage MP

Noel Bennett

Jo Jackson

Alan Burgess

Adrian Melson

Steve Dymond

Maxine Melson

Anthony Farrugia

Barry Ward

Adrian Goodyear

Clair Walton

Su Gorman

Agenda

1. Introductions and Apologies
2. New Contaminated Blood Support consultation
 - a. Aspects of the new proposals
 - b. The new scheme administrator
 - c. Plans for engagement
 - d. Proposed meeting with Lord O'Shaughnessy
3. Update on actions from the last meeting
 - a. Expanded membership of the APPG
 - b. Hillsborough-style inquiry and letter to Bishop James Jones.
 - c. Submission to the Health, Disability and Work Green Paper
 - d. Update on correspondence with Alliance House and scheme administrator trustees
4. Dates of the next meetings
5. AOB

Minutes of Proceedings

Item 1 – Introductions and Apologies

Those present introduced themselves and apologies were received from members as listed above.

Item 2 - New Contaminated Blood Support consultation

2a Diana Johnson's office and the Secretariat provided an update on the new Government consultation. It was noted a key barrier to an acceptable support scheme was the setting of the budget prior to assessing the level of support required.

It was also noted that the consultation distorts the views of beneficiaries because the views of minority groups are ignored.

A number of members left at this point due to divisions in the house but the meeting continued with Tom Stephens in the Chair and took comments from others present.

Attendees described how the proposed changes will lead to people with HIV and the co-infected losing out as they will receive lower payments under the new scheme and are losing the relative security that the Macfarlane trust provided.

The new proposals also provide no guarantee of ongoing support for bereaved partners.

Those present expressed anger that the situation has not been resolved and wondered why the Government continued to not resolve the situation despite the fact that they could find additional money if they wanted to.

Those present suggested that the APPG should take a stronger position on rejecting the consultation proposals and also calling for a public inquiry.

MPs returned and Diana Johnson resumed chairing the meeting.

2c The Chair described the activities of the APPG in raising awareness among MPs and described that its focus has been on seeking to improve the support scheme for all beneficiaries as well as campaigning for

those excluded from current support. She also referred to the APPG report on contaminated blood support that has been the basis of much of the APPG's work.

While the APPG cannot directly affect Government policy it has a role as an influencer.

Future activities could also be related to the agreed APPG position of calling for an independent panel to review what happened in the Contaminated Blood Scandal.

Action - The APPG will consider its remit and focus at its AGM in the summer.

2d The APPG has been invited to a meeting with Lord O'Shaughnessy on Tuesday 18th April although currently the position of the Minister's office is that it is inappropriate for those affected by the Scandal to attend this meeting. The Chair will write to the Minister on this point.

Action – The Chair will write to the minister regarding the consultation and the planned meeting.

Item 3 - Update on actions from the last meeting

3a The Chair noted that the APPG has been more open and transparent about their meetings and this has led to an increase in attendance from the affected community which members welcome.

The Chair also noted those who had travelled down to London for the cancelled meeting the previous week.

3b The Chair wrote to Bishop James Jones and is seeking to agree a date for a meeting.

3c The DWP received a proposals from the APPG on passporting to benefits for people affected by contaminated blood. While we are still waiting for a response on the detail of the proposal the APPG has been informed that the DWP intend to set up a working group of MPs and others on this issue as well as a user panel to advise the department.

The department has asked the APPG to put forward people to be on these two groups.

Action – Members are invited to put themselves forward to be on the working group and affected individuals are invited to put themselves forward for either the user panel or the working group.

3d The Chair informed members that Jan Barlow, Chief Executive at Alliance House had declined the invitation to address the APPG. The APPG has no powers to require the attendance of any individual.

Instead the Chair is seeking to agree a date for Chris Pond, Chair of the Caxton Foundation, to attend with the Chairs of the other discretionary charities, the Macfarlane Trust and the Eileen Trust.

Action – The Chair will agree and the secretariat circulate a date for a meeting with the Chairs of the discretionary charities.

Item 4 - Dates of the next meetings

Members and others are asked to note the following upcoming meetings:

Tuesday 18th April - 2pm: Details for this meeting will be confirmed following agreement with the office of Lord O'Shaughnessy.

Wednesday 21st June - 4pm: Part of this meeting is likely to include the APPG's AGM which will be open to members only, however non-members are welcome to attend the other portions of this meeting.

Provisionally Wednesday 11th October - 4pm

Additional meetings may be scheduled as required.

Item 5 – AOB

The potential for engagement with the Health Select Committee was discussed. Members were encouraged to approach the Chair and members of the committee to suggest they consider an inquiry into contaminated blood.

Those present welcomed Alistair Burt's letter to Lord O'Shaughnessy

Questions were asked about Nicola Blackwood's statements to parliament which were said to have misled MPs. The chair asked those present to send her more details.

There was also discussion of confusion due to the Government's use of the word compensation to describe the support scheme. This was in contradiction to repeated arguments that all payments were ex-gratia.