

**Minutes of The All Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood ng**

**Held on 9 February 2016**

**Attending**

Diana Johnson MP- Chair	Nadhim Zahawi MP	Kevin Hollinrake MP
Andy Slaughter MP	Margaret Ritchie MP	Mark Durkan MP
Christopher Stephens MP	Kit Malthouse MP	Drew Hendry MP
Chris Matheson MP	Chloe Smith MP	Barbara Keeley MP
Alison Thewliss MP	Helen Whatley MP	Kevin Foster MP
Jason McCartney MP	Gerald Kaufman MP	Anne McLaughlin MP
Maggie Throup MP	Huw Irranca-Davies MP	Steve Rotherham MP
Jessica Morden MP	Jim Cunningham MP	Albert Owen MP
Gordon Marsden MP	Mary Glindon MP	Bob Stewart MP
David McNeilage on behalf of Graham Evans MP		
Narinder Puri on behalf of Alberto Costa MP		
Stuart Drakes on behalf of Joan Ryan MP		
Tom Stephens on behalf of Tulip Sadiq MP		

**NB please note the meeting was very full and some attendees may not have been noted. Please contact Diana Johnson MP or Liz Carroll Secretariat ([liz@haemophilia.org.uk](mailto:liz@haemophilia.org.uk)) if your name should be added to the list.**

**Apologies**

Sir Peter Bottomley MP	Stephen Doughty MP	Jessica Morden MP
Harriet Baldwin MP	Baroness Meacher	Caroline Dineage MP
Graham Evans MP	Anne Main MP	Andrea Jenkyns MP
Frank Field MP	Baroness Finlay	Liz McInnes MP
Catherine West MP		

## In attendance

Liz Carroll CEO, The Haemophilia Society – Secretariat.

Diana Johnson opened the meeting by welcoming everyone. Diana highlighted that the Government's proposals and consultation had been long-awaited but that she and other MPs had been contacted by many people affected who had concerns. Diana reminded members the APPG had written to the Minister and had hoped for a response before the meeting but this was not possible. The Ministers office had been in contact to say they would provide a detailed response, but it would take time. *NB the response arrived to Diana's office during the meeting and has since been circulated.*

Diana asked Liz Carroll to give a summary of the consultation and the Haemophilia Society findings to date. Diana noted the briefing provided by The Society previously sent to APPG members.

Liz thanks the APPG for the invitation to speak and gave a summary of some of the key points. However it was made clear this is still a work in progress as the consultation documents do not give sufficient data and detail to make a full analysis of the impact the proposal will have for the affected community and The Society are still gathering evidence.

The proposal put forward in the consultation does not deliver what was expected following years of work campaigning for improved support via the APPG, campaign groups, individuals and The Haemophilia Society. It is a complex document with no clear explanation of the potential impact on individuals. The headlines of more money does not seem to be reflected in the impact of those who already receive payments.

The key points highlighted were

- The five current schemes will be combined into one simple scheme, which is very much welcomed. However there is high anxiety in the community that the proposal does not explicitly say the current leadership of the 5 organisations will not be involved in any new system. This has been a clear call for several years.
- The proposal says it has broadly the same eligibility, however there are significant changes. In the new scheme children and parents of those infected are not eligible for support, nor is anyone who is newly infected by a current scheme member. This has caused significant concern as many people are dependent on current support for children particularly. It also seems very wrong not to include anyone infected by a current scheme member – accidents can happen, we know partners have been infected by split condoms etc. There are also significant changes for the bereaved.
- Access to the new generation drugs for Hepatitis C is proposed as a major part of this scheme. The DH have suggested an alternative access scheme outside the NHS England scheme, but comments it will need to pay more for the drugs as it doesn't have the NHS England discount rates. There are several areas of concern here. NICE have guidance that must be implemented from the end of February. Within this, the vast majority of people with stage one and stage 2 Hep C will be eligible for treatment from NHS England including this community. People have a right to treatment, so should be treated via the usual route. This will ensure people are seen by a hepatologist and specialist team with the safety measures in place to support them through treatment. If people are treated outside this system there is real concern for their support through treatment, the mechanism for treatment is not explained in the proposal. Nor should money allocated to support individuals pay for treatment they are entitled to via the NHS. If the treatment is able to be given rapidly via a safe method it should not be more costly than via the NHS.
- The proposal to offer annual payments to people with stage one Hep C for the first time is welcomed as there is clear evidence it has an ongoing impact on people's lives. However the new scheme proposes individual assessments for people with Stage one Hep C to assess what level of support will be offered in terms of ongoing payments. These are proposed to be carried out by a

private company, or possibly the persons GP or hepatologist. Large sums of money are allocated to paying the assessors and running the assessment scheme. This proposal suggests they will only look at clinical implications at the time of the assessment, taking no account of the long term impact infection has had on the persons education, ability to work, relationships and mental health, all of which are well documented as significant effects of Hep C infection. Importantly the proposal confirms people will be reassessed every three years and income reduced if someone's health is deemed to have improved. This is not a supportive way of providing stability and reassurance to those with stage one Hep C.

- Annual payments to those who currently receive them will, in real terms be reduced. Currently those with HIV and Stage 2 Hep C receive an annual payment of £14,794. This will be increased to £15,000 However CPI linking will be removed, that in general would mean an increase in payments over a 5 year period.
- Discretionary payments are currently paid to almost everyone who receives an annual payment as well as the bereaved, children, parents, and those who are stage 1 Hep C. These might include winter fuel payments, child supplements, low income supplements, grants for home adaptations and repairs, travel, and many more. Almost every current beneficiary will receive considerably less income due to the withdrawal of most discretionary payments. The Haemophilia Society have yet to find one person who considers they will be better off in the new scheme. The vast majority of people say they will be between £1000 a £7000 worse off a year due to the withdrawal of discretionary payments. This has been the biggest source of anxiety for people with many feeling terrified of losing their homes and ability to provide for their basic needs.
- Currently there is huge disparity in support for the bereaved. The proposal to widen to support for all partners is welcomed, however it seems to be at the expense of ongoing support. Currently those who were bereaved due to their partner dying from HIV/AIDS receive discretionary payment – however these are in fact similar to annual payments and are consistent and regular income that people depend upon. Those who partner died from Hep C currently receive no ongoing financial support. In the new proposal all bereaved partners would receive support which is welcomed. However the newly bereaved will receive equivalent of one year of their partners payment (depending on what they get). The bereaved who currently receive payment will be offered either 3x their current yearly payment as a one off, then nothing, or access to discretionary payment (however there is no indication what this would be). Those who have already lost their partner to Hep C would get no payment. This will leave those already dependent on the current system in severe financial hardship and those who lose a partner in the future with significant anxiety. Many partners have given up careers to become carers and lost so many years employment they are now at an age they have no personal pension and no employment history or opportunity, due to their partner's infection.
- Currently all financial support is discounted for benefit and tax purposes, this does not appear to be the case in the new proposal. Again this could have significant impact, particularly when many are already losing benefits due to harsher criteria and also paying for the 'bedroom tax' out of their current Skipton/MFT payments as they have adapted or disabled access homes which are 2 bedroomed, but no other suitable accommodation is available.

Liz clarified that this is not a comprehensive review of all the issues and concerns, but some key ones to highlight to date. Further research is being done to understand the full impact and implications. The Haemophilia Society have called for the consultation to be withdrawn but are also preparing a document to help the community complete the consultation in the most effective way possible, giving guidance on the sort of issues to address in each section. This will be available very soon.

Diana thanked Liz and opened the floor for comments. Issues raised included:

- Several MPs confirmed that they had been contacted by constituents about the proposals.
- Many MPs stressed that the contents of the consultation had been a disappointment. One MP pointed out that while it was assumed this would be an improvement and people were positive

when it was announced in the House, having read the document it is not the case. In fact it is hard to imagine anything worse.

- Another MP backed this up arguing that they believed most people would be worse off after the proposals and pointing out that their constituent had described the proposals as 'cruel'.
- Other MPs pointed out that the representations they had received from constituents backed-up the issues already raised at the meeting.
- There was a discussion about the consultation, and how far it will be possible to change the outcome. One MP emphasised that many people feel the proposals are a done deal and do not see it as a consultation. However, it was important to remember that this is a consultation and so the outcome can be influenced and changed. It was argued that the government have framed the debate very poorly - the process is deeply disappointing. It is important the Minister understands this and the community know they should respond.
- Another MP stressed that while a consultation normally only led to tinkering around the edges, much more than this is needed here and it is hard to imagine how to rescue this. Proposals will need a total rethink.
- A particular issue of concern was the letter sent-out with the consultation from MFT which was described as frightening.
- It was stressed that the co infected and their partners must not be lost in the process, as much of the proposal is about Hep C.
- The new scheme must be accountable, unlike the current systems. It was argued that along with changes to the way the payments are distributed it is important that it is not the same bodies, namely Alliance House, distributing the funds.
- There was a discussion about how far the Government proposals met the recommendations of the excellent and comprehensive APPG inquiry document and whether there could be a comparison of what people asked for and what is included as some points are positive, but the negatives outweigh them.
- **Action point: to compare the APPG inquiry report and reference group notes to the current proposal.**
- Liz Carroll pointed out there was also a reference group on 5 October and the majority of what was said there has not been included.
- It was pointed out that the situation in Scotland is different; with higher payments proposed for many, as well some form of pension suggested for widows. Scottish MPs present indicated they expected the proposal to be accepted by government (it was done differently with a reference group drawing up the proposal). The final outcome in Scotland will be known before this consultation closes.
- The situation in Wales was raised. LC commented it is not yet known what Wales and Northern Ireland plan, but it is expected they were waiting to see what came out before making decisions locally.

Diana Johnson MP said she has been asked by the Contaminated Blood Campaign to say they want the consultation withdrawn.

Diana was asked if she had made a press statement as many local papers were interested. Diana hasn't made a statement but did give a comment to one newspaper when the consultation was first launched.

Diana then put forward some suggestions for the members to consider on next steps.

- Options include asking the Minister to attend a meeting to listen to the APPG concerns, it would need to be considered whether this was a public or closed meeting and which would be most likely for her to attend and have impact. This was considered a good idea, but there was concern she may say it isn't possible due to an ongoing consultation which could prevent the Minister commenting. It was pointed out that while the APPG attempts to open meeting where possible this causes many practical difficulties: it is difficult to secure large meeting rooms in Parliament, it is never possible to

accommodate everyone who would like to contribute and it is very expensive for people to travel to London to attend meetings (a cost which the Trusts would not reimburse).

- The APPG could write to the Minister signed by as many members as possible expressing concerns and try to get the consultation withdrawn. The APPG needs to decide if calling for it to be withdrawn is appropriate and likely to succeed, or whether trying to influence it to become an acceptable proposal is better. The general consensus was a letter expressing concern was supported, but maybe waiting for the response to the current letter would be helpful as it may explain some thinking and reasoning.
- A Back bench debate to highlight the issues again. This was agreed as positive.

After discussion about the possible options and potential outcomes the following action points were agreed.

#### **Action points:**

- **To reconvene when the APPG has had a response to the current letter to see if it gives reassurance or leaves the concerns open. To aim for a meeting immediately after recess the week of 25 February. This will enable discussion on next steps.**
- **To ask the Minister for a closed meeting following a response to the current letter**
- **To apply for a Back Bench Debate In March as slots may be getting full, a draft motion can be prepared, aiming for it to be a divisible motion so it is held on the floor of the house but it is important to hear from the Minister first so presumptions aren't made**
- **If there is no satisfactory result an open meeting could be held.**

It was pointed out by several MPs that their constituency members had commented they are not going to fill the consultation document in as it is not fit for purpose. **It was recognised that although this is understandable, this is not going to have a positive outcome and it is essential people complete it giving clear examples of how the proposal will affect them. This is the only way to influence the outcome positively.** Liz Carroll commented they had heard this too and are going to be advising people to fill it in and will produce a document to help. She also expressed concern about the mental health and wellbeing of the community, as this has had a devastating impact. The AAPG members agreed.

Concerns were raised over the accessibility of the online proposal and where people can go for help. It was highlighted Diana Johnson MP has asked for a helpline number as we know when we did the APPG inquiry which was much simpler than this, many people needed help to complete the survey, this has not been forthcoming.