

Minutes of APPG on Haemophilia and Contaminated Blood, 17th April 2013
Committee Room 6, House of Commons

Attending:

MPs

Anna Soubry		Parliamentary Under-Secretary (DOH)
Harriet Baldwin	Con	West Worcestershire
Tom Clarke	Lab	Coatridge, Chryston and Belshill
Jim Cunningham	Lab	Coventry South
Mark Durkan	SDLP	Foyle
Lynne Featherstone	LD	Hornsey and Wood Green
Paul Goggins	Lab	Wythenshawe
Lady Sylvia Hermon	Ind	North Down
Damian Hinds	Con	East Hants
Diana Johnson	Lab	Kingston upon Hull (Co-Chair)
Jessica Lee	Con	Erewash
Jason McCartney	Cons	Colne Valley (Co-Chair)
Jessica Morden	Lab	Newport East
Yasmin Qureshi	Lab	Bolton SE
Geoffrey Robinson	Lab	Coventry NW
Steve Rotherham	Lab	Liverpool Walton
Andrew Selous	Con	SW Beds
Andy Slaughter	Lab	Hammersmith
Owen Smith	Lab	Pontypridd

Peers

Lord Patrick Jenkin of Roding

Heidi Nicholson Parliamentary Asst to Jonathan Evans MP Cons Cardiff North.

List of Apologies:

MPs

Ronnie Campbell MP
Jonathon Evans MP
Lynne Featherstone MP
Mike Gapes MP
Damian Hinds MP
David Jones MP
Dr Philip Lee MP
Caroline Lucas MP
Stephen Williams MP
Jenny Willott MP

Peers

Baroness Finlay
Baroness Meacher
Baroness O'Cathain
Lord Owen

Baroness Randerson
Lord Wigley

Jason McCartney MP (JMc) welcomed everyone and asked Parliamentarians to introduce themselves. He noted a reassuring turnout. He asked that people give their personal stories and encouraged them to ask questions. He emphasised that the APPG was there to help and confirmed that at the moment there were no new policies to be announced. He felt that a new Backbench debate was overdue, and it was worth presenting a new case with an aggressive motion. He asked Chris James (CJ) to say a few words about World Haemophilia Day events. He then asked for questions that people wished to raise with the Minister.

Glenn Wilkinson (GW) asked JMc to clarify the APPG's position for who it represents and JMc confirmed that the APPG represents both those with and without a bleeding disorder. GW also stated that he felt the 2 stage system was divisive and disproportionate to the level of suffering within the community.

The Minister joined the meeting.

GW asked the Minister about progress following the meeting of 29 November on the Caxton Criteria and two-part staged Skipton payments. GW questioned if the Minister had spoken with Professor Brian Gazzard, Chair of the Expert Group of Hepatitis C, about his opinion on the appropriateness of a 2-stage system. The Minister could not recall and said she would come back following the meeting.

ACTION

GW also questioned if the Minister had considered the question raised by Charles Gore, CEO of the Hep C Trust at the November meeting if payments are for reduced life expectancy or living with disease. Again the Minister said she could not answer. **ACTION.** Diana Johnson MP (DJ) reminded the Minister that she had been sent a list of questions by Chris James (CJ) prior to the meeting. The Minister said the question asked was different to the one on the list - DJ did not accept this. The Minister agreed to come back with a response. **ACTION**

Jo Peaty (JP) questioned the Minister about whether she would wait for Penrose findings before support mechanisms are next altered. The Minister said she was open minded and would be interested in the findings of the Penrose Inquiry. She explained she has to take advice from experts and officials but wants to listen to what those affected have to say as well. After being reminded that people are dying at a rate of one a month, she did state that work did not have to wait until Penrose reported. JP also asked if after all the reviews/expert input, she felt the current mechanisms are appropriate. The Minister estimated that there were 800 victims. CJ advised the Minister of the correct figures 4,670 infected with HCV of whom 25% were also infected by HIV. Approximately 900 people had died in the first years after the infections. Approximately 1,800 have now died. It was clarified that this was people with bleeding disorders and did not include the group infected through transfusions. The Minister didn't feel the numbers were that substantial to pose a barrier to a solution and explained that if victims had been able to prove liability they would have been entitled to substantial

damages, but the issue was how we move on from past events to boost funding. The group agreed they needed justice. The actual numbers need clarifying. **ACTION.**

JMc reminded everyone we're on the same team. The Minister also summarised what she thought people wanted – more money in the pot and rule changes.

GRO-A gave a personal story of her son's death while on HCV treatment with Telaprevir and how his bereaved partner and child had very distressing problems with Skipton & Caxton and in her view were treated disgracefully. Minister agreed it sounded a dreadful case. JMc confirmed that MPs hear a lot of cases like this and asked the Minister to take that thought with her.

The Minister confirmed she had spoken with the various funds to make clear it is not acceptable and changes are happening. But she has major concerns over the set-up of some funds and the fact there are so many and the bureaucracy that makes people feel they are begging and beholden. She couldn't make promises but will look at it and recognises some just want a lump sum and to get on with their lives while for others their condition may need a different arrangement.

Graham Manning (GM) asked why it takes so long to sort anything out. The Minister expressed similar exasperation and said after she has looked at things, if she can identify a time-scale for a review, she will report to the APPG. A comment was made that the systems set up by successive Governments are divisive and people are being dealt with in an uncompassionate and ineffective way.

The Minister was asked a question about the possibility of getting Ireland-style payments in the UK. She repeated the Government line about Ireland being different because it was based on a court finding and that liability was shown. JP challenged Minister. She was corrected by Mark Durkan MP (MD) who told her that the initial payments had been made in Ireland before any admission of liability. The previous Government had retold the fiction several times that the compensation scheme in Ireland rested on liability, but that scheme existed in Ireland before the finding of liability. The Minister asked if the system established was based on quantum and clarity was required. **ACTION**

A man gave a personal story of an offer of a £500,000 liability payment which he turned down as he believed the UK Government would sort it but he's still waiting. He called for closure - 'You can't give us our health back so give us our dignity.'

A woman gave a personal story of losing her husband in 1985 and bringing up 2 daughters. She still has to work and recently approached the MFT about a, leaking front door. She found the MFT unhelpful and uncaring. The whole process had been humiliating. The Minister agreed this was not acceptable and asked the woman to ask her MP to write to her directly.

GRO-A stated we shouldn't be considering improving Trusts, but just pay lump sums or fair on-going payments.

Collette Wintle (CW) explained that the community don't just want an extension of funds. She described how her cousin in Ireland had compensation and then went back and received further compensation and it means they can get on with their lives. No UK Government has done anything to sort it out. Also, it's wrong for Haemophiliacs to have to go through DWP re-assessments about fitness for work given their situation. The Minister couldn't help on DWP but acknowledged a powerful point and urged MPs to take up fight.

Lesley Brownless (LB) questioned if after reviewing pots of money, will the 80% left out last time be included. The Minister said she couldn't make any promises but she did say "I'm profoundly unhappy with the situation". She said it "feels wrong" but has belief previous Governments did have best intentions but the process was badly thought out.

LB also commented that loss of potential isn't recognised. Victims can't make up the time of illness since age 20 even if cured 30 years on. The Minister agreed and said quantum would address that in legal action.

Nick Sainsbury (NS) asked if any costings were done for removal of Stage 1&2 distinction. The Minister replied that she did not believe they have been. She stated that she wanted to rethink the whole thing, and have it properly costed out. She would look into on what basis the figures reached. **ACTION**

Andrew March (AM) asked about progress of the Expert Group on Hepatitis C review report. The Minister said she doesn't know anything yet. **ACTION**

A man stated that the Minister made some encouraging noises but would she use Penrose as a reason to delay acting. The Minister said she was interested to know the Penrose findings but didn't see why action shouldn't be taken to help sooner.

Lynne (LK) and Nick Kelly (NK) made a point about lack of data on Hepatitis C both in the general population and within the bleeding disorder community. They felt proper data is required before costings of compensation can be made. Secondly despite substantial support from Members and Peers in successive governments the Government had failed to sort anything out and we're here again.

The Minister agreed and she felt all the different kinds funds were ridiculous.

Andy Slaughter MP (AS) called on APPG to provide follow up to questions and issues raised and provide feedback to members. He expressed the opinion that there was widespread support but lack of understanding on why nothing gets sorted. The Minister agreed but believes there are much bigger questions to answer.

Lynne Kelly (LK) explained that an acknowledgement of what happened is what everyone wants. JMc confirmed MPs made that point in the 2010 HOP Debate. JM suggested another BackBench Business Committee Debate with a voteable motion would be a positive move. This was welcomed by the meeting. **ACTION**

Tom Clarke MP (TC) described the efforts made by Lord Morris and urged the Minister to familiarise herself with the Bill he put through the Lords and Commons; perhaps then we can make progress which has been lacking for the last decade or longer. **ACTION**

Jessica Lee MP (JL) urged the Minister to look at the lump sum settlement that would make so much difference & questioned progress on the MFT funding for 2013/14. The Minister agreed the situation does not feel right and referred to quantum settlements again. **ACTION**

JMc thanked everyone and especially the Minister, explained they all have substantial workloads and issues impacting on the Treasury but reiterated support for the community above all. He confirmed questions provided to the Minister would be followed up on, action to get an update on the Expert Group, rationale from the Irish situation, accurate statistics, and also why we can't get these funds together and get them to work better for the victims. He finished the meeting by saying that improving the financial system for victims of the contaminated blood disaster would be his top priority if any money could be found. He stressed that we were on the same side and the attendance at the meeting proved what support there was from Parliamentarians of all sides.