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Statement No: WITN3988001

Exhibits: WITN3988002-WITN3988093

Dated: 30 July 2020

EXHIBIT WITN3988043

Issues : Haemophilia Society

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Below is the list of Issues as discussed today, I have raised all of these with the Haemophilia Society:

The Society is focused on Women with Bleeding disorders and newly diagnosed families not those affected by contaminated blood. I feel they have failed to address any of the issues facing this group.

MPs in the APPG are being given mixed messages from the Society and their Constituents as all APPG members are representing constituents infected with HIV / Hep C or bereaved families. In my experience the only parents who contact their MPs are those who have a family member with contaminated blood. Haemophilia care generally is very good and patients wouldn't feel the need to contact their MP.

The new Chief Executive of the Haemophilia Society Liz Cowell met with the APPG to plan the meetings for this year which will include an Introduction to Bleedings disorders and highlighting the Society's work with women. I do not support this.

The letter from the group of MFT beneficiaries 26th Feb 2014, asking the Haemophilia Society to support a vote of no confidence in the MFT was not discussed at the Haemophilia Society Board Meeting 19th March. I haven't seen the original letter I only received a copy of the reply on the 27th March which was sent to **GRO-A** on 26th March which does not support the beneficiaries request. I have replied to Liz and Bernard Manson and the Board of Trustees saying that it was not discussed or agreed by the Trustees. I do not support the decision and if asked by anyone I will say just that.

At the Haemophilia Society Board Meeting 11th September 2013 I raised Issues regarding constituents who had contacted me in Wales about the MFT and Caxton Funds. The MFT had asked the Haemophilia Society to appoint a Trustee, I felt the Society should not appoint a Trustee as this would be taken as a sign of approval of the Funds.

Haemophilia Society Board Meeting 27th November Alan Burgess and Mat Gregory MFT Trustees telephoned into the Society, the Society had received a document from a group of MFT beneficiaries outlining the problems with the MFT. I agreed to send details of Welsh patient experiences of the Trust to Mat Gregory (although I know he was well aware of the issues as he was previously a Haemophilia Society Trustee and I telephoned him when I was first contacted about issues relating to the MFT). I didn't have Alan Burgess' email address and I asked Bernard Manson Chair HS to forward to him, he confirmed he had done this on the 28th Nov.

I attended a with meeting the co Chairs Diana Johnson MP and Jason McCartney MP at the beginning of 2013 to agree the direction of the APPG. Jason McCartney stated that he wasn't interested in Haemophilia, he gets asked every day of the week to support

various charities but the only reason he became involved with the APPG was because of the contaminated blood scandal, he is representing his constituents who are infected with Hep C and VCD who are not all Haemophiliacs.

Owen Smith MP who is no longer a member said that when he attended APPG meetings there was never a clear message about what the Society wanted them to achieve, he said that MPs were all fired up and ready to go and the message they got from Chris James the previous CeO was about the Fit for the future initiative. They thought they were there to get an acknowledgement, Public Inquiry and financial support. He said it just didn't make sense. MPs weren't interested in the day to day work of the Charity, they just wanted a clear concise message without too much detail. Owen Smith was my cousin's MP and it was he who instigated the 2010 debate.

My MP Jonathan Evans believes that we should be focusing on Archer recommendations as this covers Haemophilia care and financial needs of all Haemophiliacs of all ages. To date the Society has failed to press for the implementation of Archer, has been unable to secure any of it's recommendations regarding a Statutory Committee on Haemophilia to advise on treatment and financial support, Insurance, Cards and HS Funding.

I feel the Society is also responsible for the failure of the Haemophilia Alliance Meetings. Lord Archer's recommendation was a Statutory committee to advise the Govt on both treatment and financial needs of Haemophilia patients. The Terms of Reference of the Haemophilia Alliance meetings do not fulfil these recommendations as financial needs were not included. The Society should not have agreed to this. Consequently when patient representatives raised issues regarding financial support the DH said that it wasn't in the remit of the Haemophilia Alliance Meetings

Sir George Young told my MP Jonathan Evans that he hadn't witnessed anything like the Contaminated Blood Debate 2010 in all his years in Parliament, with so much genuine support from so many MPs (38 spoke about their constituents). I have raised this issue many times at the HS Board Meetings and have asked the Society to contact these MPs to re engage with them, this has never happened.

Unless we give the MPs in the APPG a clear direction which must reflect their constituents needs they will not attend the APPG meetings and will lose interest, this has happened in the past and will happen again.

I feel it is inappropriate to spend APPG meetings learning about bleeding disorders and learning about women with bleeding disorders, I have 3 sons with Haemophilia, I also have low clotting levels but realise that there are more immediate unresolved issues that the APPG should be dealing with related to those men and women affected by contaminated blood.

Regards

Lynne