

Cross Party Group Meeting

25th June 2019 Committee Room 5, Ty Hywel, Cardiff

Attendees

Kirk Ellis
Sybil Fowler
Christine Fox
Martin Fox
Glenis Gill
Jan Goldsworthy
Phillip Goldsworthy
Meinir Elin Gooch
Cynthia Hill
Christian Howells , Barrister 30 Park Place
Rosemarie Howells
Annette Hutchings
Elaine Huxley
Lynne Kelly
Tony Lane
Brian Longford
Janet Morgan
Lucy O'Brien Watkins and Gunn
Joyce Olszweski
Toni Olzweski
Glesni Sibley
Barbara Sugar
Craig Sugar
Graham Sugar
Margaret Sugar
David Thomas
Jean Thomas
Christine Williams
Jason Williams
Lloyd Williams QC 30 Park Place
Tony Lane
Patricia Summers
Tony Summers
Helen Cook
Ian Wallace

AMs

Mick Anotiniw AM and Chair
Nancy Cavill (Julie Morgan's asst)
Hefin David AM

Jane Hutt AM
Mark Isherwood AM
Dai Lloyd AM
Jill Purvis (Huw Irrancca Davies)
Austin (Mick Antoniw)
Francis Rhun ap Iwerth)

Apologies
Rhun ap Iwerth AM
John Griffiths AM
Sian Gwenllian AM
Vikki Howells AM
Huw Irrancca Davies AM
Jeremy Miles AM
Carol Harker
Chris Harker
Edward Purnell
Gill Purnell
Margret Sharpe
Sue Sparkes
Gerald Stone
Bev Tumelty

Mick Antoniw AM and Chair of the Cross Party Group opened the meeting and welcomed everyone. Mick confirmed that he had written to Vaughn Gething, Minister of Health and Social Services asking Welsh Government to act quickly and to end the disparity of support across the UK for infected and affected as requested by Sir Sir Brian Langstaff Chair of the Infected Blood Inquiry.

160 victims have died across the UK since the Infected Blood Inquiry was announced 11th July 2017. Mick circulated a copy of the letter to the group and confirmed that Welsh Government had not been given prior notice of the English announcement 30th April 2019

Dr Dai Lloyd AM stated that payments should come directly from the UK Treasury and not from Welsh Government the contaminated blood disaster was pre devolution.

Hefin David and Dai Lloyd have asked questions in Y Senedd about Infected Blood support . Dai Lloyd received a reply from Vaughn Gething 13th June saying here will be a meeting of UK Health ministers before the summer recess but that he expects there will be another consultation before any decision is taken.

Mark Isherwood asked if there was a Barnett consequential for Infected Blood support. It was confirmed there was no new funding for the recent English announcement 30th April. Historically HIV was funded by the DH and Hep C by Welsh Govt. It is unclear how the Wales Infected Blood Support Scheme (WIBSS) is currently funded.

Tony Lane informed the group that last week in Parliament Diana Johnson had asked for immediate compensation now. David Thomas stated that he met David Lidington Minister of the Cabinet Office and Jackie Doyle Price with the other UK campaigning groups and charities and the proposal put to them was for UK wide support for infected and affected, but the announcement on 30th April in England did not reflect their demands.

Kirk Ellis outlined the importance of ongoing support for widows, he is deeply concerned that his partner and young son should not have to beg for discretionary support should he die. He would prefer for the Scottish scheme to be put in place as he sees this as being a fairer, although ongoing payments for infected are £1k less per annum he wants security for widows and partners to be a priority.

Toni Olszweski Hep C said that he had recently been ill and was concerned that his Hep C had returned a she had relapsed on other occasions following treatment. He was initially refused a Hep C test at his GP surgery as 'it was too expensive'. When he said that he would get a test done privately it was carried out and came back positive. He was extremely worried about the result and was referred to the Blood Borne Viral Clinic where further testing was done and the virus was non detectable. This has been extremely

stressful for Tony and he would like the availability of Hep C testing and monitoring of Hep C patients post treatment to be examined by the Inquiry. He was discharged in 2017 following successful treatment with Exviera, Viekirax and Ribavirin with no liver follow up and feels this is not acceptable due to long term affects of Hep C.

In 2012 MFT consultation to 'pass the bulk of it's financial reserves reserves onto it's beneficiaries who took part in face to face interviews, telephone calls and a 20 page questionnaire. A year later widows were informed there would be no change to the £19k benchmark for non infected widows.

2018 MFT reserves were passed to THT. David Barlow was appointed as MFT Beneficiary support manger but is no longer in post. Tim Waldron has replaced him. Beneficiaries have been unable to access any funds and Tim Waldron says another consultation is planned. Action : The Cross Party Group to write to the Terence Higgins Trust asking for a meeting with them as the group are concerned that the money held by the THT we be used for another consultation and there will be no funds remaining in the THT.

Lloyd Williams QC and Christian Howells gave an update on the Infected Blood Inquiry. They have attended all Hearings in London, Northen Ireland, Leeds and will be in Edinburgh for the next 2 weeks.

Witnesses selected for the Cardiff Hearings at the Royal Welsh College of Music 23rd-26th July will have been contacted. If people are not called to give oral evidence their statements are of very important and will be read by Justice Langstaff.

There will be 12 witnesses in Cardiff and 9 of those are from Haemophilia Wales and being represented by Watkins and Gunn. Lloyd said that Sir Brian Langstaff Chair of the Public Inquiry is regularly making the point about the disparity in financial support across the UK and the Inquiry is getting a good impression of how

people are impacted. Sir Brian is very open and approachable and engages throughout the day in coffees breaks etc. Lloyd and Christian have not seen this before with other Judges. The Inquiry has 150 paralegals examining documents and 6-10 experienced Inquiry solicitors. The Inquiry has received 5 million documents from 2 Government Departments. They have retrieved documents from US drug companies with offices in London. There are 3 further weeks of witness have been added in October for witness hearings as over 2000 people have come forward and provided statements. Sir Brian is reading all witness statements personally
Tony Lane is concerned that the Inquiry will be never ending but Lloyd Williams confirmed that this will not happen. Sir Brian wants to hear all the evidence carefully, he knows time is of the essence and that there is a balance between thoroughness and speed.

From 2020 the decision makers will give evidence : civil servants, doctors, modern day experts, Hep C experts medical experts in ethics dealing with disclosure to patients. Dates of knowledge will be examined and Ken Clarke, John Major, David Owen will be giving evidence The group felt it would be appropriate for an interim decision to be made as many people will not see the end of the Inquiry. There continues to be a reluctance on the part of UK Government to accept responsibility for payments

Lloyd Williams wants the devolved regional experts to give evidence. There will be further hearings for campaigners, there will be a focus on treatment and funding.

One member asked if doctors can be named . Lloyd Williams explained that they are rep NI and there was a submission from the barrister representing a doctor but this request was quashed by Sir Brian and Jenni Richards Inquiry QC.

Issues around out of date data was discussed and it was agreed to seek further advice from one of the Hepatologists.

The APPG on Haemophilia and Contaminated Blood Chaired by Diana Johnson MP and the UK Haemophilia Society Inquiry have recently launched an Inquiry into access to Haemophilia treatment.

Haemophilia Wales and Haemophilia Scotland were not informed of this and were not invited to the APPG. Haemophilia Wales regularly attends APPG meetings but had no knowledge of this. The CPG and Haemophilia Wales have lobbied both Welsh Government and Westminster Government to establish a full UK wide Judge led Public Inquiry. This was not the preferred option of Diana Johnson as her constituent wanted a Hillsborough style Inquiry let by the Bishop of Liverpool and a panel. Julie Morgan Chair of the CPG stood firm and would not agree to sign a letter endorsing the APPG's view on October 17th 2017 as this was not the view held by the CPG and Haemophilia Wales, patients and families in Wales. (See attached letter from Julie to Diana Johnson)

Issues relating to Haemophilia treatment are raised at the All Wales Advisory Group on Inherited Bleeding Disorders, set up following the Ministerial review of Haemophilia care in Wales consisting of patient representatives, Haemophilia Wales, Haemophilia doctors, nurses, Physiotherapists, Psychologists and social workers, Local Health Board officials and Welsh Health Specialised Service Commissioners. Any unresolved issues can then be taken to the Cross Party Group via constituents Assembly members or Haemophilia Wales or directly by constituents as everyone is welcome to the CPG meetings.

Action CPG to contact Welsh MPs and Diana Johnson MP

NB Access to Longer Lasting Treatments for Haemophilia is not an issue in Wales

Haemophilia clinicians in Wales do not have the same restrictions placed on them as England when prescribing the longer lasting Haemophilia treatments. Wales has a tailored approach to the longer lasting Haemophilia treatments and if patients are suitable candidates then they can be prescribed the treatment with no restrictions. The new longer lasting treatments do not suit everyone and some Haemophilia patients revert to standard Haemophilia treatment.

It was agreed that Haemophilia Centre staff would be welcome to attending the Infected Blood Inquiry Hearings.

Integrated medicine or alternative therapies was discussed for infected blood victims with a poor prognosis. The group agreed that this would offer some hope and comfort where conventional medicine had failed and should be raised with the Inquiry.

Actions

CPG to set up meeting with Vaughn Gething

CPG to contact Welsh MPs and Diana Johnson re APPG Inquiry on access to Haemophilia treatment

CPG to ask for a meeting with Tim Waldron Macfarlane Trust

Beneficiary Support Manger at the Terence Higgins Trust

LK to seek advice from Hepatologist re out of date data

Integrated medicine and alternative therapies to be raised with the Inquiry.

Next meeting August/ September 2019