

Haemophilia CPG

Wednesday 6 July 2016

Media Briefing Room, Senedd

11.30 – 12.30

Attendees:

Julie Morgan AM

Dai Lloyd AM

Neil McEvoy AM

Jane Hutt AM

Helen West (Office of Julie Morgan AM)

Rachel Booth (Office of Julie Morgan AM)

Natasha Shafer (Office of Jane Hutt AM)

Kathy Bevan (Office of Huw Irranca-Davies)

Lynne Kelly (Haemophilia Wales)

Patients

Inaugural meeting and AGM

Julie Morgan AM elected as chair – nominated by Dai Lloyd

Dai Lloyd AM elected as vice chair – nominated by Julie Morgan

Julie welcomed everyone to the first meeting of the Haemophilia and Contaminated Blood Cross Party Group.

Patients introduced themselves and described their experiences with Hep C and Haemophilia.

Julie introduced AMs in attendance and the staff from their offices.

Following their earlier meeting with the Cabinet Secretary for Health, Well-being and Sport, Vaughan Gething, Julie asked Lynne Kelly and the patients to update her and the group on the situation surrounding ex-gratia payments for Haemophiliacs and their families.

Lynne Kelly described how she met with Alun Cairns in April and he said that the responsibility for the payments was with Welsh Government. There has been no comprehensive communication between Westminster and Cardiff Bay. The Scottish government have said that the Welsh government haven't been very co-operative. The Haemophilia and Contaminated Blood All Party Group meeting at Westminster, Jane Ellison said that there would be no Barnett formula for the money to be given out in payments, so Welsh Government would have to find the money. However, Lord Brampton said there would be the Barnett Formula so everyone is in a state of confusion.

The Mcfarlane Trust (set up in 1988 by the British Government to support people with haemophilia who were infected with HIV as a result of contaminated NHS blood products, and their spouses, parents, children and dependants) widows payments come from the Welsh government for Hepatitis C. It is believed that families will be £8-10 thousand worse off with the new English system of payments.

Welsh government should implement the Scottish scheme of payments – much more generous. Scotland have admitted their responsibility and have been more compassionate than England and Wales. Welsh government not accepting responsibility to help.

There will be nothing to patients who are living with the financial effects of having the disease.

The Irish scheme of payments much better than Scottish scheme.

Dai Lloyd said that that Wales should meet with Scotland and Ireland to discuss the payments. Wales must show compassion and help those affected by contaminated blood.

Discussion with patients - they described the mental strain of not only having the disease but also having to deal with the stress of the changes in payments. 5000 patients infected in 1980s – 2000 have died so far. The patients feel like the government is waiting for them to die so they don't have to pay

compensation. The patients were infected with blood collected from prisons in America.

Julie asked what the group should do to move forward. Need to find out from Vaughan Gething what is happening. Need to make direct links with Scotland and Ireland. Julie and Lynne to meet to discuss the way forward. Members of the group need a meeting with Vaughan Gething on a cross party basis.

Julie thanked everyone for coming and the meeting was brought to a close.