

Cross-Party Group on Haemophilia and Contaminated Blood Annual Report and Financial Statement: 2013-2014

Purpose of the Group:

To raise awareness and improve treatment and support for people with Inherited Bleeding Disorders.

Membership of the Group

Julie Morgan AM Chair
Lynne Kelly Secretary (Haemophilia Wales)
Mick Antoniw AM
William Graham AM
Kirsty Williams AM

The Group did not meet with any professional lobbyists
The Group met 3 times: in October 2013, June 2014 and November 2014

AGM and Cross Party Group Meeting Haemophilia and Contaminated Blood: 23rd October 2013

Attendees :
Julie Morgan AM
Mark Drakeford Minister Health and Social Services
Mick Antoniw AM
Kirsty Williams AM
William Graham AM
Sian Mile, Senior Research Officer, Julie Morgan
Caroline Lewis assistant to Mark Drakeford
Lynne Kelly Haemophilia Wales
Haemophilia patients and bereaved families from Wales
Staff from Cardiff Haemophilia Centre

Julie Morgan was re-elected as Chair and Lynne Kelly was re-elected as Secretary of the Group. The Health Minister Mark Drakeford joined the meeting and agreed to take questions from the floor. The outstanding issues of the Task and Finish Group's Review of Haemophilia Care in Wales were raised by the Group, the lack of financial support for those affected by contaminated blood and the Penrose Public Inquiry into Contaminated Blood in Scotland. The Minister confirmed that funding was in place for the Consultant Hepatologist at UHW and he would raise the issues of financial support with Jenny Randerson. The Minister agreed to consult with the devolved administrations when Penrose reported.

Cross Party Group Meeting Haemophilia and Contaminated Blood: 4th June 2014

Attendees:
Julie Morgan AM and Chair of CPG
Mick Antoniw AM
Dr Chris Jones Deputy Chief Medical Officer WAG,
Sian Mile, Senior Research Officer, Julie Morgan
Lynne Kelly Chair Haemophilia Wales

Craig Sugar Trustee Haemophilia Wales
David Thomas Trustee Haemophilia Wales
Pat Summers Trustee Haemophilia Wales
Tony Summers Trustee Haemophilia Wales

The Haemophilia Physiotherapy post at Swansea was advertised and the new Physiotherapist at Cardiff had been appointed. The Group discussed with Dr Chris Jones their disappointment at the lack of progress with the Consultant Hepatologist post at UHW. The CPG asked Dr Chris Jones to consider funding the new Hepatitis C drug Sofosbuvir with Ledipasvir (Harvoni) for 8 Haemophiliacs with Hep C who were at risk of decompensated liver disease pre NICE approval. Financial support from Macfarlane Trust, the Skipton Fund and the Caxton Fund were discussed. All beneficiaries report difficulties accessing inadequate payments from the Funds which are badly administered and not fit for purpose. At Westminster, the APPG on Haemophilia and Contaminated Blood and Alistair Burt MP are sending surveys to all beneficiaries.

AGM Cross Party Group Haemophilia and Contaminated Blood: 26th November 2014

Attendees:

Julie Morgan AM Chair of CPG
Jane Hutt AM
Mick Antoniw AM
David Rees AM
Vaughn Gething's assistant Temmy Woolston
Sian Mile, Senior Research Officer, Julie Morgan
Lynne Kelly : Haemophilia Wales Chair
David Thomas Trustee Haemophilia Wales
Pat Summers Trustee Haemophilia Wales
Tony Summers Trustee Haemophilia Wales
Richard Gorman Trustee Haemophilia Wales

Julie Morgan was re-elected as Chair and Lynne Kelly as Secretary; the Group thanked both for their work through the year. The Consultant Hepatologist post at UHW is now advertised and the Haemophilia Physiotherapist at Swansea is appointed. The Interim Commissioning Policy funded treatment for 2 Haemophiliacs who had contracted Hep C via NHS blood products pre NICE approval. It was agreed that the CPG would ask the Health Minister to fund the new Hep C treatment for Haemophiliacs with Hep C who had previously failed Interferon based Hep C treatments. The absence of adequate financial support provided by the Macfarlane Trust, Skipton Fund and Caxton Fund was discussed. The school uniform grant and winter fuel allowance cuts were causing increased hardship with no provision for life assurance or mortgage protection. The Group noted that the Penrose Report and the APPG Inquiry into Financial support for Haemophiliacs infected with Contaminated Blood would report in 2015.

FINANCIAL STATEMENT: 2013-2014

Group's Expenses	None	£0.00
Cost of all goods	No goods purchased	£0.00
Benefits received by the group or individual members from outside bodies	No benefits received	£0.00
Any secretariat or other support	No financial support received	£0.00
Services provided	Refreshments paid for by Haemophilia Wales (Oct 23 rd 2013) and Julie Morgan AM (November 26 th 2014)	
Date	Provider	Cost
October 23 rd 2013	Charlton House	£68.28
November 26 th 2014	Charlton House	£63.72
	Total cost	£132.00