

Cross Party Group on Haemophilia and Contaminated Blood

Tuesday 18 July

12.30-2pm

Pierhead Seminar Rooms 1&2

Attendees:

Julie Morgan AM

Jane Hutt AM

Mark Isherwood AM

Hefin David AM

David Rees AM

Dr Dai Lloyd AM

Caroline Jones AM

Hefin David AM

Mike Hedges

Helen West AMSS

Nancy Cavill AMSS

Gill Purves AMSS

Lynne Kelly

David Thomas

Craig Sugar

Pat Summers

Evelyn James

Janet Morgan

Barbara Sugar

Jodie Sugar

Margaret Sugar

Cynthia Hill

David Farrugia

Diane Scott

Dorothy Woodward

Gerald Stone

Diana Edwards

Jean Thomas

Glesni Sibley

Gaynor Lewis

Tony Olsweski

Christine Fox
Michael Imperato, Watkins and Gunn
Rhodri Williams QC
Christian Howells
Ian Edwards
Debbie James
Kay Parfitt
Bev Tumelty
Ian Wallace
Jan Goldsworthy
Rachel McGuinness
Linda Watts
Brian Watts
Brandon Preston
Anna Preston
Jennifer Williams

Apologies

Rhun ap Iwerth AM
Neil McEvoy AM
Vikki Howells AM
Angela Burns AM
David Melding AM
Mick Antoniw AM
Janet Finch-Saunders AM
Simon Thomas AM
Llyr Gruffydd AM
Tony Summers
Sue Sparkes

Julie began by welcoming everyone to the first meeting of the Cross Party Group since the announcement on 11th July 2017 about the launch of an Inquiry into contaminated blood by the Prime Minister. There has been some improvements with payments to affected patients and families and the new

scheme will be administered by Velindre NHS Trust. Wales has played a major role, especially Lynne Kelly who has worked tirelessly. If people work and commit long enough to a campaign you can achieve. There of course is a feeling of loss as so many people have died in the long campaign to get the inquiry.

AGM: Julie nominated as Chair of the CPG, Lynne Kelly nominated as Secretary.

Lynne gave a brief overview of the campaign for an inquiry. Started in 1980 and Haemophilia Wales has taken the lead, many of the original members have now died. Don't want another inquiry like the Archer inquiry where the Department of Health refuses to take part. Patients and families all need to know the truth.

There was then a discussion with group members:

Everyone in Wales affected by the contaminated blood needs to sing from the same hymn sheet. Important to have a strong voice in any inquiry. It is essential to find out the timescale of the inquiry. Patients and families have already had to wait 30 years for this announcement and they need to ensure that they will get the answers to what went wrong.

Mike Imperato (Watkins and Gunn) has met with many families to hear their stories. The Lawyers wrote to Jeremy Hunt to challenge the decision not to hold an Inquiry and gave them 14 days to call an inquiry or there would be a full judicial review. The inquiry was announced on the 14th day.

It was agreed that the CPG should be called for evidence and contribute to the inquiry.

In 2015 David Cameron gave a personal apology and £125 million towards the public scandal. House of Commons also issued an apology but neither called for a public inquiry. They were both in reaction to the Scottish inquiry.

The UK wide inquiry could take years – they have thousands of records to go through and have to make sure it is done properly.

Mike Imperato is going to write to the Department for Health to say that he won't give up the legal battle until we know what type of inquiry it is and all the details.

Mike Imperato called on members of the CPG to write to him if they would like his firm to take up their case and represent them in the inquiry.

Everyone needs to keep the pressure up and the inquiry needs to start in 2017.

Concerns about who decides who the chair of the inquiry is – will it be the Prime Minister, the government or the Department of Health. Legal challenges can be made if there is a sign of bias, or if wrong decisions are made.

Under the 2005 Inquiries Act, an inquiry can be chaired by 1 person or a panel of experts etc. The group agreed that it should be a High Court judge or above.

The group talked about the format of the Hillsborough inquiry. It was first a panel that looked at all evidence and documentation which led them to decide that a full inquiry was needed.

It is important that everyone affected has some form of legal representation that can act on their behalf and support them in the inquiry.

Haemophilia Wales's connection with Watkins & Gunn was discussed. They were the only firm that agreed to speak with Lynne and others at Haemophilia Wales. Mike Imperato at Watkins & Gunn met with Haemophilia Wales and agreed that he would support the campaign for the inquiry. He then wrote to the UK government to request an inquiry. Some people affected have been approached by other legal firms who would like to represent them and giving 28 days to reply. It was discussed that it was probably best to all be represented by Watkins & Gunn so everyone is united under one firm.

The inquiry can find instances of failure and make recommendations. It will look into the role of pharmaceutical companies, the blood service, Department of Health.

Some people affected were asked to sign disclaimers for HIV payments/settlement. Patients were put under pressure to sign a waiver against taking legal action against the government.

Andy Burnham when he was an MP said that medical records were altered to cover up what was happening.

What should be covered by the inquiry?

- The government knew the risks
- People were tested for infection, but then weren't told that they were infected
- Role of the pharmaceutical companies, blood service, Department of Health
- Delay in informing people that they were infected – could have passed on Hep C, HIV without knowing
- Families of patients weren't asked if they could donate blood rather than have anonymous blood
- Why did they give so many people the contaminated blood? Men, women, children all affected.
- Colin – 2 year old boy infected by contaminated blood. He died when he was 7 years old. Why wasn't there an inquest into his death?
- Doctors telling families not to tell patient that they had been infected by contaminated blood
- Specific Welsh concerns – Welsh blood service
- Why Haemophilia Society issued an apology

When the chair of the inquiry recognises the core participants funds will be available for legal costs. Haemophilia Wales and the CPG needs to be a core participant.

Members of the group should start getting medical records and information ready to make sure they have everything prepared for the inquiry.

Issues about death certificates were discussed. Lots of families didn't want Hepatitis C or HIV on the death certificate. Victims don't have the real cause of death on certificates.

Alcoholism was the reason given by doctors for many of the symptoms of contaminated blood.

Project in the British Library 'HIV and the family'. Has recordings of interviews from 30 widows affected by HIV.

The payments that families have received have been appalling.

Wales is ahead in terms of the lifesaving drugs available for Hepatitis C patients. On the way to eliminating the disease. England is lagging behind.

Lynne and Haemophilia Wales will collect ideas of things that should be covered in the inquiry.

It is important that the inquiry is completely independent. There mustn't be medical staff on the panel who can influence other panel members by saying 'it was the best treatment at the time...' etc.

It is thought that British patients were given US blood because they thought it was safer as it was heated to a higher temperature. Turned out it was the worst blood that patients could have been given.

The role of Haemophilia Scotland and Haemophilia Northern Ireland was discussed. Scottish government is not pushing for a public inquiry but would want to participate. They will provide all the evidence from the Penrose Inquiry.

The meeting was brought to a close and Lynne thanked everyone for their coming and their contributions.