Witness Name: Julie Morgan
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Dated: 23 September 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN2438003

CPG on HAEMOPHILIA AND CONTAMINATED BLOOD

October 23rd 2013
Conference Room C

Sponsored by Julie Morgan AM

AGENDA

Chair: Julie Morgan AM

12:15: Opening – Julie Morgan AM
12:15-12:20: Introductory Remarks – Mark Drakeford AM, Minister for Health and Social Services
12:20-12:25: Progress to date – Lynne Kelly, Haemophilia Society
12:25-12:45: Questions and comments from the floor

There will be time for discussion until 1:15/1:30 pm after the Minister has left at 12:45 pm.

1.Introduction

23rd October 2013

Welcome to the Cross Party group Meeting on Haemophilia and Contaminated Blood and thank you all for coming. I'm Lynne kelly I have 3 sons with Haemophilia and am a Trustee of the Haemophilia Society. Mark Drakeford the Health Minister will be attending at 12.15, this is the first time a Welsh Health Minister has agreed to meet us in an open meeting and take questions from the floor and I would like to thank Julie Morgan for all her efforts in organising this today.

It is important that we remember that we are amongst friends, our AMs and clinicians have listened to our concerns and I hope that Mark Drakeford will take these issues forward.

Mark Drakeford is only in the room for half an hour and so we have 5 questions from patients and affected families which address the main issues. Refreshments will be served at 1pm and then there will be an open discussion.

2nd Intro : Thank you Mark Drakeford on behalf of the Haemophilia Society for agreeing to meet with us and take questions from patients

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2.History

The journey so far as you all know has been long and traumatic.

In Wales in the 1970s and 1980s 226 Haemophiliacs were infected with Hepaitis C , 40 were also infected with HIV through contaminated NHS Blood products. Many were infected as babies and children.

67 of those infected have now died one of whom is a close relative

and the contamination of the general population with the spread of Hep C is a growing problem which continues to be a cause of alarm.

In 1999 the Irish governments response to the contaminated blood disaster was the Lindsay Tribunal which announced a full care and compensation package for those infected.

In 2009 the Archer Inquiry, recommended a full care and compensation package in the UK in line with Ireland.

BUT the UK government have remained stubbornly in denial of the problem and as a result 12 years on and **the Archer recommendations have not been implemented**

In Wales the Blood Borne Viral Strategy Plan 2010-2015, has been drafted to improve service provision to patients with Hep C,

and a Task and Finish Group was set up to review Haemophilia care in Wales.

3. Issues in Service Provision

In July Earl Howe Parliamentary under Secretary of State for Quality said that ' That the patient should be at the centre' he felt that the exclusion of the patient in developing services is often the reason for failure'

Through **Engagement** with the Haemophilia Society, patient representatives and clinicians

the Task and Finish Group's Haemophilia Review identified

- gaps in Consultant Hepatology care at Cardiff,
- gaps in Physiotherapy through out Wales
- and the need for Psychological support

and we can celebrate some significant successes in these areas as a result of listening to the needs of the patients and maintaining a strong dialogue with clinicians and AM's

- 4 Psychologists have been appointed
- The nurse led Blood Borne Viral Clinic is operating well, patients with Hep C but without advanced liver disease have access to Fibroscans.
- Problems with access to Hep C drugs for patients attending Cardiff haemophilia centre and living in other areas have been solved with the help of Assembly Members contacting the Local Health Boards directly on behalf of their constituents.
- At Swansea a 2nd Haematologist is being recruited
- Physiotherapists at Bangor and Cardiff are about to be appointed

4. Unresolved Issues in Service provision

However despite these successes there is still much to do

- The Physiotherapy post at Swansea is unresolved due to lack of funding. The post is only 2 days a week and will provide outreach to Withybush Hospital.
- Without Local Health Board and Gastroenterology representation on the All Wales Advisory Group, chaired by WHSCC progress is impossible. It was agreed in May 2012 that a representative from the national Specialist Advisory Group on Gastroenterology would be invited to the meetings and 18 months later this still hasn't happened.
- Liver disease:

  There are 12-14,000 people with Hep C in Wales. Only 2.5% of these have contracted Hep C through blood or blood products.

  The British Liver Trust, The Hepatitis C Trust and the Haemochromotosis Society as well as Haemophilia patients all report difficulties in accessing specialist Consultant Hepatology opinion in Cardiff.

  Yet patients with liver disease in their diagnosis account for 1 in 10 patients in UHW critical care.

  The report "Improving liver health and out comes in liver disease in Cardiff and Vale of Glamorgan Dec 2011" identifies a future service model which remains un implemented.

  The representative from the National Specialist Advisory group on Gastroenterology who was part of the Haemophilia Review stated that " without the appointment of a consultant Hepatologist at Cardiff the care of this group of patients would not improve"

- David Sissling Chief Executive NHS Wales, made one of the main objectives in his Annual report 2013 to 'reduce Emergency Admissions'

  how can that be achieved when patients with advanced liver disease are not being monitored, there is no single pathway of care, there is no dedicated Hepatologist and they are being admitted through A and E or through the Haemophilia Centre.

- **Data:** The University Hospital of Wales had the highest Hospital Death rate scores in Wales this year and we would ask if the enormous gap in service provision for patients with liver disease is a reason for this?

5 . conclusion

- In 2009 Nicola Sturgeon Scottish Health Minister established the Penrose Inquiry to provide answers and closure for victims of contaminated blood in Scotland. In March 2014 Lord Penrose will report on the circumstances leading to infection of Scottish Haemophiliacs with NHS blood products.

  What will the Welsh response be to Penrose in Scotland?

- In 2015 The Wales Blood Borne Viral Action Plan Strategy comes to an end?

  Will consultant Hepatology be in place?

- **There is a deeply felt need by relatives, friends and patients themselves for the enormity of the contaminated blood tragedy affecting them to be recognised and explained**

- In 2009 Lord Archer recommended a full care and compensation package for all Haemophiliacs infected with NHS blood products in line with what had been received by Irish Haemophiliacs. As we have seen we are still addressing the provision of care and nothing except denials have been heard on the matter of compensation or the acknowledgement of the disaster.

- **In PMq's last week Alistair Burt MP again raised the question of an apology for the tragedy and financial support for victims**

- In keeping with Lord Archers recommendations we would ask the Welsh Govt for a commitment regarding clinical services and financial support for Haemophiliacs.

- We are asking for an acknowledgement to the contaminated Blood disaster from the Welsh Govt and we propose a Welsh Public Inquiry before the 2016 election.

- The Cross Party group on Haemophilia and Contaminated Blood was set up in 2011 to Raise awareness and improve care and support and we are asking for your continued support to ensure that we meet these objectives.

and now we will hear from patients and family members about how these issues are affecting them...

CPG Meeting Haemophilia and Contaminated Blood 23rd October 2013

Questions from patients and affected families to Mark Drakeford Health Minister

1) In 2010 my brother died from Hepatitis C and liver cancer, he wasn't monitored at UHW and the liver cancer was discovered too late. It is now 2013 and nothing has changed. I am in the same position as my brother, I attend Cardiff Haemophilia but my liver disease is not being monitored as there is no Hepatologist. I am attending the Royal Gwent Hepatology, nurse led Clinic but there is a 6 month wait to see the Consultant Hepatologist.

   Question : Why has it taken so long to appoint a consultant Hepatologist at Cardiff?

2) I have advanced liver disease and was given with Hep C as a child through NHS blood products. I have never seen a liver specialist at the Heath. I have failed Ribavarin and Interferon treatment 3 times ,I have had to keep working as I have a family to support. I cannot get life assurance. '

   Question: Why is it when I have been infected with Hep C by the NHS in Cardiff through no fault of my own, I can't get access to specialist opinion, I haven't received compensation and can't get life assurance?

3) A Swansea mum's perspective. We have 2 small rooms assigned to haemophiliacs in Swansea and south west wales one houses the assigned nurse , the other the treatment room. There is no where to sit . They need bigger rooms for treatment and consultation. They put us in the corridor outside the rooms to wait . There is a notice board for the world to see who and what we are and I feel that this is a very serious breach of confidentiality. One consultant is assigned to treating who is hard to get to as he is the resident haematologist and also lectures I believe.

If he is not available then there is a lot of hunting around for a registrar to make as assessment.

The assigned nurse has now had some administrative help . We get a physio occasionally on loan from Cardiff. my son gets an annual review which is not enough.. We also have a psychotherapist 2 days a week. The Nurse is very stretched and has to do ward rounds in the morning. So, if you have a crisis try and plan it before rounds or after 12 noon.

After hours is a complete lottery as we have to go to Morriston not Singleton where the unit is. It depends who is on call. There is an excellent make nurse who knows the routine but which Doctor you see is completely random and very few have an understanding of the condition.. No assigned parking space makes it difficult to park near the centre. I applied for a blue badge and limited disabled parking so adds to

the stress looking for a space when your son cant walk. No specific space for a haemophiliac or drop off point.
I had to justify the need for blue badge to my GP , hard carrying a teenager when he can't walk if he has a bad bleed in the knees or ankles. '

Question: Why is it taking so long to appoint a 2nd Haematologist and a Haemophilia Physiotherapist at Swansea?

4) My Son died from Contaminated blood, leaving widow and dependant, The Archer Enquiry proved beyond doubt that our, sons, brothers, and husbands were infected by receiving contaminated blood. There have been many meetings ,both here and in Westminster, seeking help , pleading and holding out the begging bowl. We should never have been put in this position ,but we are. The finances of widows are being more & more stretched, and their ability to support their children, education ,clothing or even a little holiday becomes increasingly difficult.

   The Skipton Fund and the MacFarlane Trust are becoming increasingly pedantic in their ability to provide funds for our desperate families. Constantly changing rules and form filling add stress to the situation.

   All the counselling and moral support does not pay the bills or give a child the comfort of saying 'My Daddy bought me this'

   Question: We have been told that this is not a devolved issue, but we question that. The giving of contaminated blood took place in Wales, so we feel that the Assembly cannot ignore the plight of their infected constituents.

   We, they, need financial help. The problem is not going away. Every meeting, and correspondence ends with the words "The Minister will look into this."

   How can the Minster and our Welsh Assembly help us to meet the needs of our widows and children?

5) Spouse of infected haemophiliac

Question: '**When will the Welsh Government acknowledge the Contaminated Blood Disaster? When will they set up a Public Inquiry? Will the Welsh Government respond to the Penrose Inquiry findings in 2014?**