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Presentation Welsh Assembly

Gareth Lewis Haemophilia Wales

"Behind each adverse event there is a patient, a doctor, and a doctor-patient relationship we also have a politician. A patient must be told when things have gone wrong. Every effort must be made to minimise the afier effects, including financial recompense where necessary. Most patients wish to know in detail what happened and what is being done to reduce the possibility of a recurrence. And members of healthcare teams need mechanisms to come to terms with their fallibility. It is hoped that clinical governance will make a difference."

I would be grateflil if you could shed some light as to why the above has still not happened with regard to the contamination of haemophiliacs through NHS blood products. This issue was described in the House Of Lords this year as the biggest medical treatment disaster in the history of the NHS, yet no public inquiry! I do not hear haematologists standing up and supporting their patients in the fight for a public inquiry, indeed there is a wall of silence! Will you AMs of the welsh Assembly remain silent

Haemophiliacs in Wales, want their day ofjustice, indeed as doctors are well aware part of the psychological healing process is coming to terms with the truth about what has occurred.

Haemophiliacs are unable to move on with what is lefi of their lives until this happens in an official capacity such as a public inquiry.

It has been lefi up to haemophiliacs and their families to dig for that truth largely unsupported. The following should leave you in no doubt as to what we are having to confront and we ask why haven't the so-called professionals/government told us the truth.

Haemophiliacs not only have to deal with professionals with holding information but also with professionals inappropriately transferring their anger onto patients because their patients have stumbled onto the truth.

The Facts:

1. We are of course aware that the Department Of Health and haematologists blatantly ignored WHO guidelines in the 1 970s and used imported American factor concentrates, that is a country with a low incidence of hepatitis
imported blood products from a country with a much higher incidence of hepatitis, plasma collected from high-risk populations within a higher risk country.

2. We are aware that the Department Of Health and haematologists ignored the literature and research available at the time which studied and documented the greatly increased risks of using blood obtained from paid, skid-row donors such as those shown on the 1975 "World In Action" documentary "Blood Money".

3. We are aware that plasma collected for Factor VIII and other blood products was obtained in large quantities from the captive "high-risk" donors of prisons such as Arkansas, Louisiana and Arizona. Indeed we are fighting now for justice with the families of some of those prisoners who went on to die of hepatitis C. Some prisoners even had the wrong blood cells put back into their bodies during plasmapheresis, equipment sometimes used on more than one patient increasing the spread of viruses.

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4. We are of course aware that plasma was obtained from "high-risk" donors in third world countries in Africa, ("high-risk" for viruses such as HIV and hepatitis), Central America etc, the poor and sick exploited by unscrupulous blood-brokers who were rewarded with influential positions on the World Federation O f Haemophilia such as vice-chairman.

5. We are aware that human blood was relabelled as animal blood to avoid customs, and blood from cadavers was relabelled as having come from live donors.

6. We are NOW aware of the reason why a hepatitis waiver was included in an HIV ex-gratia payment, an attempt to silence haemophiliacs and prevent future litigation should a haemophiliac survive Aids.

7. We are aware that many haemophiliacs were misinformed both by the Department Of Health and haematologists with regard to the hepatitis C virus in 1991 being told "it was nothing to worry about" and "less of a problem than hepatitis A or B," despite hundreds of articles Ire search papers, books, stating a very different picture.

8. We are aware that many haemophiliacs were not even tested for the hepatitis C virus until 1994 despite accurate tests being available at a much earlier date.

9. We are aware that haemophiliacs are frequently told by haematologists that the "benefits of treatment outweighed the risks." In Newcastle alone out of 105 patients tested for HIV, 95 tested positive, 77 are now dead, 95% of those surviving haemophiliacs have hepatitis C usually in addition to hepatitis B. Very successful treatment! !!

10. We are aware that the Department Of Health and many haematologists assume all haemophiliacs and their families are stupid and haven't got the intelligence to fathom out why so many haemophiliacs were infected with HIV and hepatitis C and are now dead. This assumption is incorrect!

We talk to you today as the Assembly members responsible to ask what support will you or your party offer haemophiliacs to highlight the issues raised, bringing them to the attention of the wider political audience as we are doing, and what support will you or your party give to help us fight for a public inquiry.

Well I won't beat about the bush,

let's talk about the type of places the major pharmaceutical companies bought their blood from, let's talk about cummins situated in Grady, Arkansas and the plasma centre.

If you make a transatlantic call, a certain former Governor of Arkansas will I'm sure be able to give you all the details you want on the prison plasma program.

Write to John Byus, the Medical Administrator who knows all about the hepatitis status of the some of the prisoners contributing to the plasma program.

You may also wish to look at the history of Alpha Therapeutics, in particular Green Cross, or where Cutter bought its plasma. Check out Armour, Baxter and Bayer, defendants in American law suits brought by infected victims.

Then check out this country's existing plasma purchase records.

I wonder if Government expected all HIV infected haemophiliacs to be dead before hepatitis C reared its ugly head.

Haemophiliacs now have a choice of which virus they die from.

Do you really expect surviving haemophiliacs and their families to remain silent on this issue.

Would you remain silent if your wifeor husband was infected with HIV, hepatitis B and hepatitis C through contaminated NHS blood.

It seems to me that the Welsh Assembly and this Government has a choice, you can save face by announcing a public inquiry yourselves, (a good will gesture pre-election.) and offering a hepatitis C compensation package simular to Cannada Southern Ireland

The press here are becoming very interested in the ongoing criminal investigation into the blood in (Canada) and the public inquiry about to start in Ireland. We also have the evidence from the Italian inquiry.

The press are also interested that this country can no longer use its own plasma because of the "theoretical" risk of CJD. ("The greed with the feed" story, messing up the food chain and putting humans at risk once again.)
Do you want this Assembly and this Government to be reported in the press as caring about contaminated blood recipients or covering up a huge international blood scandal?

The choice is yours!

I end this with the following quote.

"To be silent in the face of injustice is to be an accomplice to evil. I will not be silent."

I await your reply.