Witness Name: Lynne Kelly
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HAEMOPHILIA WALES
Registered Charity No: 1158941
Telephone : GRO-C

June 13th 2016 ; Baroness Featherstone and Lord Prior meeting

1. The use of the Fund to pay for Interferon Free Hepatitis C Treatments

Enhanced access to treatment should not be part of any financial support proposals.

There are major shortcomings in the existing evidence base for Haemophiliacs and we believe there should be a prioritisation process for the following reasons:

- Haemophiliacs were infected by the State, many as babies and children, at a time when alternative treatments were available. The State has a moral duty of care to those who are infected.

- The Haemophilia community are not represented or included in the Advisory Group on Hepatitis expert advice to the Department of Health in 2013.

- The Haemophilia community were not considered or consulted by NICE as part of the evaluation of the new Interferon free Hep C treatments.

- The expert advice and evaluation fails to correctly access the QALY for HCV sufferers with Haemophilia, all have been infected for over 35 years, their Hep C progresses quicker due to the long incubation period and are they more likely to die than those in other situations.

- Access to specialist consultant Hepatology opinion has been patchy through out the UK and many have been unmonitored for liver disease. Many have died as a result of the true impact of the virus being undetected.

- Haemophiliacs have been exposed to multiple Genotypes of Hep C from up to 20,000 donors per injection. Severe

Haemophiliacs were exposed hundreds of times which was an assault on the immune system causing immune fatigue.

- Conventional epidemiology Hep C factors are not relevant to our group as they do not engage in high risk activities and will not re infect themselves.
- The cost of not treating Haemophiliacs places significantly more burden on the NHS, medical investigations such as endoscopies, biopsies and liver transplantation are significantly higher in the Haemophilia population. Factor replacement costs for haemophiliacs, particularly those with Inhibitors and HIV all increase costs to the NHS.
- Home treatment (often daily) for Haemophilia patients places additional risk of family members contracting Hep C.
- Prevalence of mental health and emotional distress related to Hep C is 35%higher than the general population.
- Incomplete data : Mortality rates of contaminated blood patients in stage 1 /stage 2 category : There is no data held for deaths of stage 1 Hep C as the Skipton Fund or DH are not notified of these deaths.
- The UKHCDO only collect the Fact of death and not the cause of death.
- Hep C status prevents access to life assurance and mortgage protection.

2. The Welsh Issue

All Haemophiliacs with Hep C in Wales have been treated with the new Hepatitis C drugs.
The contaminated blood disaster happened before devolution.
Many Welsh Haemophiliacs travel to England for their Haemophilia care and were infected in English hospitals.
The current proposals are for England only.
There was a meeting on 24th March 2016 with DH and Welsh Govt officials.

3. The ongoing need for an Inquest

There is a deeply felt need by patients, families and bereaved families for the enormity of the contaminated blood disaster to be recognised and understood.
There is an on going need for an Inquest into the deaths as the deaths were caused by the State and these deaths have not been investigated. Unlawful killing Article 2 Court of Human Rights as the State has caused the death of over 2000 Haemophiliacs due to systemic and systematic failures.

4.The Consultation itself
In 2009 Lord Archer recommended payments in line with the Republic of Ireland.
In 2014 the APPG survey into financial support, Alistair Burt's YOUGOV survey , the DH's Reference Group's meeting October 5th 2015 all provide a true assessment of what is needed:
Lump sum or ongoing payments
Ongoing support for widows and dependents
Statutory Inquiry
Access to Hep C drugs.

The Haemophilia community find the consultation proposals, January 2016 insulting after over 30 years of campaigning for improvements. Under the new proposals, those who currently receive anything will be worse off by up to £7,000 per year and those who receive nothing will continue to do so.

Scotland March 2016 : After a full consultation Nicola Sturgeon accepted all the recommendations of the Financial Review Group and will be increasing ongoing support, providing a pension for widows and a 1 off payment for stage 1s, and a hardship fund. (see letter to Jeremy Hunt)

Lynne Kelly 12.6.16
Chair of Haemophilia Wales

www.haemophiliawales.org
Email: info@haemophiliawales.org
Facebook : https://www.facebook.com/haemophiliawales

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