

TRANSCRIPT

Programme(s)	Radio Four The World Tonight
Date & time	Wednesday 3rd April 2002 22:30
Subject / interviewee	Haemophilia / Zeinab Badawi Report
Prepared by:	David Griffiths
Contact numbers:	GRO-C - Pager GRO-C - 24hrs, every day

Robin Lustig: Lord Owen who as David Owen was a Labour Health Minister in the nineteen seventies is calling for a Parliamentary inquiry in to why six thousand British haemophiliacs were exposed to life threatening viruses from contaminated NHS blood products? It has been described by some leading doctors as the worst treatment disaster in the history of the NHS. Haemophilia is a rare genetic illness which affects only men, their blood won't clot so they have to receive regular injections of the blood clotting agent factor eight. Which means that every haemophilia patient over the age of seventeen may well have been exposed to either HIV, the virus that can lead to AIDS or to hepatitis C or indeed to both. Lord Owen believes that the risk comes from contaminated blood imported from countries that paid blood donors who could have included drug addicts. While he was health minister he announced a ban on blood imports but it was never put in to effect and he is now demanding to know why? When? And by whom his policy was overturned? There is a government fund to compensate haemophiliacs who have been infected with HIV but not those who have been infected with H, hepatitis C. Even though more than two hundred haemophiliacs have already died from illnesses linked to it. And there are fears that the numbers are rising. Zeinab Badawi reports.

Zeinab Badawi: Most parents treasure moments like these with their children.

GRO-A: **GRO-A:** you naughty boy, you used all those (UNCLEAR), **GRO-A:** you naughty boy, you had two of their lives...

GRO-A (Haemophiliac): **GRO-A:** is the elder one, she is, she is quite a bright kid, I think she gets here intelligence from her mother rather than me, along with her good looks.

Zeinab Badawi: **GRO-A:** has recently been performing in a school play but for **GRO-A:** these things have an added poignancy. He is one of the country's five thousand haemophiliacs who has been infected with hepatitis C through contaminated blood products, he has developed liver disease, diabetes, asthma and psoriasis all believed to be linked to his hepatitis C.

GRO-A: Haemophilia is something that I have grown up with. It is something that I have always had to manage, so to me haemophilia was my norm. After the hepatitis C I had, it seems to have escalated all the problems that affect me. Also now I have diabetes which is a direct result of the hepatitis C and I also now have psoriasis which I developed from interferon for the treatment of the hepatitis C. And I seem to be going on and on getting more and more things wrong with me.

Zeinab Badawi: Doctor Paul Jangrandee is Director of the Oxford Haemophilia Centre. He explains how hepatitis C can lead to fatal illnesses.

Doctor Paul Jangrandee (Director, Oxford Haemophilia Centre): Eighty percent of people who are exposed to hepatitis C will become chronic carriers. The virus remains in the liver and it replicates, it divides and it causes inflammation which is painless so the patient doesn't know that it is actually taking place. The time course of the inflammation is slow and typically after about twenty years in a significant proportion, we will see sclerosis, that is scarring of the liver, with liver failure. But the chronic inflammation can also in a small proportion of patients, actually cause liver cancer.

Zeinab Badawi: *The Labour Peer Alf Morris has long campaigned on behalf of haemophiliacs in this country. A former Minister for the Disabled in the seventies, he doesn't understand why the government give compensation to haemophiliacs with the AIDS virus and not those with hepatitis C. Ministers say the HIV payments were unique and awarded in the face of exceptional circumstances. But this isn't good enough for Lord Morris.*

Lord Morris (Former Minister for the Disabled): We couldn't prove negligence, medical negligence in the case of HIV infection, that wasn't argued at all, what was argued was that hundreds of people, thousands of people in the haemophilia community had been infected by contaminated NHS blood products.

Zeinab Badawi: *So you say the government responsibility towards haemophiliacs in, infected with hepatitis C is a moral responsibility?*

Lord Morris: Well it was said by government itself that they were meeting a moral responsibility when they compensated people for HIV infection. So there is no difference in principle.

Zeinab Badawi: *Since nineteen eighty five all donated blood can be screened for HIV and hepatitis C. But now haemophiliacs have been dealt another blow. GRO-A from GRO-A is a severe haemophiliac who had already been infected with both the AIDS virus and hepatitis C. last year he learned he had been given blood from somebody who had died of variant CJD, the human form of mad cow disease. Dismayed and distraught, GRO-A dumped his blood products and demanded treatment using recombinant factor eight. This is a synthetic alternative to blood plasma but it is more expensive and in England it is only automatically given to haemophiliacs under twenty. GRO-A is thirty five, he didn't qualify for it so he went on treatment strike for three months and ended up in hospital after a serious attack of bleeding.*

GRO-A (Haemophiliac): The pain was so severe I just could not take it any more. I was literally vomiting with the pain. I had to give in, I had to take blood based products, they, they sent me home after a week and again I was back on the strike. I refused to take any blood products home with me. You shouldn't have to fight for safe treatment and if, and if a few of us do and manage to get it then perhaps that will open doors for others to have it.

Zeinab Badawi: *Doctor Jangrandee agrees and says at present treatment using recombinant amounts to a flagrant post code lottery.*

Doctor Jangrandee: All patients with haemophilia in Scotland and Wales receive recombinant products and yet it is rationed in England and Northern Ireland. The way forward is clear, we have a product that is available, the patients have suffered enough already, they face anxiety, let's switch to this product which is available now. We have supposed to have a national health system with common standards, that clearly doesn't apply here.

Zeinab Badawi: *There is another question for the government that is being raised. Is the mass infection of Britain's haemophiliac community a tragedy that could have been largely avoided? When David Owen was a Labour Health Minister in the mid seventies, he introduced a policy of self sufficiency blood. He is angry that when he became Foreign Secretary the policy was changed at some time without himself or Parliament being informed. Now he is taking steps to find out more.*

Lord Owen: I asked for my papers as Minister for Health and I was told that they had all been pulped and there is some bizarre ten year rule which struck me as very odd because I, all my papers as Foreign Secretary are available to me. But they were not available. But now I have gone back over a television interview which I gave at the time when I was asked a direct question and I make it quite clear that I was worried about the quality of the blood transfusions and blood products coming from the commercial sector where people have been paid for it. And there are other evidence which makes it clear why I had made the decision now in seventy four. And I hope the Ombudsman will re-open the case, make a judgement now that the administration had taken place and get some compensation scheme for people who have got the hepatitis C virus in their blood stream and some people now developing one of the side effects of it, which is cancer of the liver.

Zeinab Badawi: *Lord Owen's concerns are adding to calls for a full public inquiry. Last year in Ireland such an inquiry resulted in haemophiliacs with hepatitis C receiving compensation of up to eighty thousand pounds. Countries like Italy, Sweden and Canada have already done the same. But health ministers here are still opposed. And all the while haemophiliacs like GRO-A in Bristol wait desperately to see if their campaign for justice will at last be heard?*

GRO-A: Because of the way things are now, I can't, I can't get life insurance so I can't make any provision whatsoever for my children. I would, I would love to be able to, to play a game of football, I would love just to be able

to play. It, it is not physically possible, we don't live, we survive the same as any, anybody does on, on, on benefit. I am just a burden basically.

Robin Lustig: *That report was by Zeinab Badawi. We did ask if we could talk to a Minister about all this but we were told that no one was available. Instead the Department of Health gave us a statement. It says the government has given careful consideration to the case put by the Haemophilia Society but does not believe that there are grounds for providing financial assistance to haemophilia patients with hepatitis C on a no (UNCLEAR) basis or that a public inquiry is justified. In the five years since this issue was first considered no new evidence has been presented to the Department of Health that changes the government's position.*

END.