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GRO-C

Tel GRO-C

28th September 2004

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RE CONCERNS OVER VCJD RELATED TO OUR FORMER COMPLAINT

Dear Mr Tim- Cox Brown,

Thank-you for your letter of 15th September 2004.

You may have seen a number of press reports related to an exercise to assess haemophiliacs in terms of vCJD risk from plasma treatment. This came about following the first case of a person dying from v CJD following a blood transfusion. A second person was identified as incubating v CJD on post-mortem, following a blood transfusion, although this was not the cause of death.

I have enclosed the notification letter from the hospital plus information sent to us. I have also sent my reply. This is relevant, as part of our original complaint was about not being informed back in 1997, which was the first time the RVI hospital received a letter from a plasma company warning of vCJD exposure to haemophiliacs through their treatment. It even listed the specific batch numbers.

We were only officially told of my husband's exposure in 2001 after we got hold of leaked letters, one from the plasma company in 1997 and the other from the NHS Executive in 1998, advising not to tell haemophiliacs. We sent these letters to the press in protest and as a result the government were pressurised to contact haematologists, asking them to write to patients and ask them if they wished to know of v CJD exposure. The letter from Peter and I to Dr Kate Talks, GRO-A current haematologist should be self-explanatory and deals with our issues of concern, some of which formed part of our original complaint.

We note that in 2001, Dr Peter Jones actually sat on a BSE/CJD world advisory committee on how to deal with this issue in relation to the haemophilia community, (see e-mail). At the time he was my husband's consultant, however, he and Dr Hamilton failed to inform their own haemophilia patients in 1997 of their vCJD exposure. We believed this to be unethical and were concerned that the "don't tell haemophiliacs" attitude may have put family, health service staff, and other patients at risk.

We first wrote to Dr Jones as far back as 1995, asking for Peter to be put on recombinant synthetic treatment, because we feared the risk of v CJD. We were turned down in March 1996 and Peter's first exposure to v CJD was in the November!

Peter now receives ongoing support from a hospice, he is in poor physical health. In terms of mental health he suffers from depression, much of his depression is related to the lies and cover-up over the contamination of haemophiliacs with multiple viruses, and as the latest news with vCJD shows, few lessons have been learnt from the previous HIV and hepatitis disasters.

We did eventually force the government to pay out for hepatitis C through the Skipton Fund, although this scheme does not include widows, we are very angry about this. Our only hope of justice is via a full and open public inquiry. A motion for this was put forward at the Lib /Dem conference. I provided much of the historical background to enable my colleague to put forward her argument. There was an overwhelming “yes” vote for a public inquiry, so this will now become part of party policy.

Thank-you for your assistance.

Yours sincerely

Carol and Peter Longstaff

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