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NHS Foundation Trust

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Prof Sir Liam Donaldson
Chief Medical Officer
Department of Health
Richmond House
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Dear Liam

You may recall that I wrote to you in September 2004 about my concerns regarding the counselling and clinical management of patients who received blood transfusion from a vCJD prion-infected donor. I also copied you my letter to Sally Davies (6 December 2004) reiterating my clinical concern. I have since had discussions with David Harper and Gerard Hetherington and my colleague Dr Stephen Wroe has had lengthy discussions with the Health Protection Agency (HPA). I understand the HPA have also been in discussion with the National CJD Surveillance Unit (NCJDSU), with whom HPA plan surveillance and related research.

Despite this, I am afraid this cohort of patients, iatrogenically exposed to vCJD prions during NHS treatment, and whom in my expert opinion are at high risk of being infected with this lethal pathogen, have still not been offered access to best practice care in the NHS (through the country's only specialist NHS clinic, the National Prion Clinic (NPC) at the National Hospital for Neurology and Neurosurgery) or the PRION-1 therapeutic trial.

Despite lengthy discussion with HPA and a further recent appeal to the Department, we have not been allowed to communicate directly with the GPs of these patients. Instead, we are asked to contribute a letter that will form part of a complex package of information being sent by HPA to GPs under a covering letter advocating referral to local neurologists. In our view this package, which I understand is trying to balance and represent a number of interests, will cause confusion and yet further delay these patients receiving the best practice care to which they are entitled. I am sure you would agree that the patients' interests must come first. I fear this unnecessary delay may mean that patients will not be seen until after clinical onset of vCJD.

It is my strong clinical opinion that these individuals should be offered NPC review and long term follow up immediately whilst they are *asymptomatic*. This will enable those electing diagnostic lymphoreticular biopsy that test positive to enter the PRION-1 trial (with the option of joining the immediate treatment arm). While we do not know if quinacrine would reduce the probability of progression to clinical disease, clearly the earliest possible intervention would give any drug the best opportunity. As you know, NPC staff can visit those unwilling or unable to travel to London.

Personally, as an NHS physician, as well as in my academic position with a national leadership responsibility in this area, I am deeply concerned at the way this matter has been handled. I believe that good clinical practice requires that these patients are provided with clear information in order to make informed choices regarding their predicament at the very earliest opportunity. This is best achieved by the specialist staff of the NPC contacting patient's GPs personally, in order to brief them fully.

I am sorry to have to bring this again directly to you. I have sought other opinion on this very difficult matter and am advised to approach you directly to ask if we can be provided with the relevant GP details as a matter of urgency. Clearly, HPA and NCJDSU have an important role in surveillance of this cohort and the public health issues arising, and their proposed information package could then follow, but I hope you will agree this should not risk confusing or further delaying direct contact with specialist NHS services.

With best wishes

Yours sincerely

GRO-C

John Collinge FRS
Professor of Neurology

Cc: Professor Alan Thompson, Clinical Director, National Hospital for Neurology and Neurosurgery
Professor David Fish, Medical Director and Robert Naylor, Chief Executive, UCLH NHS Foundation Trust