(1) Mr Eddy (by fax) - for info.

cc PS/Mrs Bowman
PS/Prin Sec
Mr Osborne
Mr Carden
Mr Meldrum
Mr Hodson
Dr Shannon
Mr M Smith

Dr Lamdle
Mr Taylor
Mr Bradley
Dr Wright

3242
1/3 29/2

(2) Minister to see

Dr R Will
Consultant Neuropathologist
Western General Hospital
Crewe Road
Edinburgh EH4 2XU

M. Nicol 21 February 1996
PS/Minister 29/2

Dear Dr Will,

Thank you for your fax dated 16 February 1996. In our previous telephone discussion you told me that because of danger of infection from urine specimens, you were having difficulty finding a suitable licensed laboratory in Edinburgh for this work. I am glad to know that you would be able to do this work now.

The urine test which I have developed for CJD does work. Recently, MAFF has granted a licence to Electrophoresis Ltd. to develop a urine test for BSE. I do not know where you got the notion that the urine test for diagnostic purposes would be exceedingly unlikely to be helpful in CJD cases.

The nature of the agent remains controversial. Dr. Prusiner believes it is a protein but too much of the evidence so far presented has been based on assumptions. I have demonstrated that the Nemavirus is uniquely typical of all spongiform encephalopathies. These findings have been independently confirmed by others.

I note, too, with interest, that Prusiner's group has recently concluded that "another" macromolecule - other than the "prion" - is required in the posttranslational process, which seems to undo the PrP gene mutation hypothesis. In reality, there are two requirements for this process to occur. i) To code for another protein, a DNA is required; ii) since all hosts have the PrP gene, to code for another protein, DNA has to be non-host. In my previous studies it had been demonstrated that this macromolecule is coded by the ssDNA of the Nemavirus. There is nothing unconventional here. This is not a slow virus. Only the disease process is slow.

I well remember the interesting discussion we had in Edinburgh in 1989. At that time, I was given the impression that I would play an active part in CJD Surveillance. I would be testing brains from every suspect case of CJD using my "touch technique" which would complement the histological test. As you know from my published work, this test works both for biopsy and autopsy tissues. I confess that I was dismayed when you failed to contact me again. I am sure you had a great deal of correspondence on these lines with Dr J W Smith then Director of PHLS. Subsequently, I received minutes of a PHLS Meeting dated 23 October 1990 stating: "Dr Smith clarified the PHLS position on slow virus work, namely, that PHLS did not wish specifically to engage in this area at present, because it was being adequately addressed by

96/02.21/5.1

other excellent research groups".

In your report "Creutzfeldt-Jakob disease surveillance in the United Kingdom" You reported 260 suspect cases. Of these 76 are definite, 62 probable, 48 possible, 48 others, 25 unclassified and 1 GSS for the period of 1985 - April 1990. Further classification of 139 notified cases for the period of May 1990- 30 April 1992, you reported 43 definite cases, 11 probable, 20 possible, 63 other and 2 not classified. From these figures you can see that if my simple touch technique was used for confirmation, we would have better scientific information and publish the accurate incidence of CJD. Since my test can be done on the same day of postmortem, correct death certificates could be issued. Further, this test would be useful for screening tissue donors so that tissues form CJD cases are not used for transplant.

I note from your many public statements that you do not believe that BSE can be passed to humans. You also say in your fax that the urine test would be "exceedingly unlikely" to be helpful in CJD cases. Given your clear beliefs in this regard, and your own department's lack of experience in dealing with the Nemavirus, I think the best way forward would be for you and I to meet, with a view to discussing terms and conditions for having my test validated. I'd strongly propose, for example, that the management and scrutineering be handled by an impartial third party, chosen by mutual agreement. As for the validation process itself, I 'd suggest that I first demonstrate my test on ten CJD positive samples and ten Alzheimers, (CJD negative) ones. In the second place, the impartial third party would select, say, ten of those samples in whatever combination he chose, and then I'd test those, blind.

With reference to paragraph three of your fax, I am at a loss to know how you could guarantee that the details of my test would not be passed to any third party. But we can discuss that too. For the moment, allow me to explain that my test has been developed with private financial backing, and that the test itself is my intellectual property.

When we meet , I think it might prove helpful if detailed minutes be taken. Would you let me know if we could meet on 15 or 18 March 1996?

With best regard

Yours Sincerely

Harash Narang.

Harash Narang.

cc Hon. Stephen Dorrell MP Secretary of Health ; Rt Hon. Douglas Hogg MP, Minister of Agriculture, Fisheries and Food; Rt. Hon. Harriet Harman MP, Gavin Strang MP, Dr David Clark MP, Mr Jim Cousins MP, Mr Ken Bell.; Northen CJD Campain Group.

96/02.21/5.2