Thank you for your letters of 8 September and 13 October to Gerald Malone on behalf of your constituents about Creutzfeldt Jakob Disease (CJD). I am sorry you have not received an earlier reply.

We share your concern that the monitoring of CJD in the UK should be as effective as possible. That is why we set up the National CJD Surveillance Unit in 1990. The monitoring system used by the Unit is kept under constant review by the Department and we are satisfied that the level of ascertainment of CJD is very high.

The Surveillance Unit maintains excellent relations with all neurologists in the UK and, especially now that clinicians are well aware of the disease, it will be rare to find a case of CJD going unreported. In fact a substantial number of cases reported to the Unit turn out not to be CJD. The Unit also receives copies of death certificates from the Office of Population, Censuses and Surveys from which one or two cases a year are identified.

I enclose a copy of the fourth annual report of the CJD Surveillance Unit, published earlier this month, which you may find helpful. I assume this is the research you referred to in your letter of 13 October.

The question of a public inquiry into the death of a son was first raised by the Today newspaper in articles published on 14 and 15 August. Copies are enclosed for your information. The Department's refusal of a public inquiry was in response to questions from the newspaper. We felt such an inquiry to be unnecessary because we have already established the independent Spongiform Encephalopathy (SE) Advisory Committee (SEAC) with a remit to advise Government on all matters concerning SEs, including CJD.

CJD in young people, although extremely rare, is by no means unique. For example, a 20 year old died from CJD in the USA in 1980 and a 16 year old in 1981. A 19 year old died from the disease in France in 1985. Creutzfeldt's first patient in 1920 was aged 23. There is no evidence
of an iatrogenic cause for those cases nor, of course, was BSE a factor. It does, therefore, seem that there are rare cases where CJD is found in younger age groups than would normally be expected.

The role of the SEAC in research is to advise the Ministry of Agriculture, Fisheries and Food (MAFF) and the Department of Health on all aspects of research into SEs, including research priorities, new work required, and advice on work in progress. MAFF and the Department of Health have responsibility for the co-ordination of that research.

TOM SACKVILLE