UNIVERSITY OF GLASGOW

REGIONAL HAEMOPHILIA
REFERENCE CENTRE

HAEMOSTASIS AND THROMBOSIS
RESEARCH UNIT
DR. C. D. FORBES

DR. G. D. O. LOWE

16th December, 1986.

The Prime Minister, 10 Downing Street, London.

Dear Prime Minister,

I am writing to you in my capacity as Chairman of the United Kingdom Haemophilia Centre Directors and also Chairman of the AIDS Committee.

I wish to draw your attention to the plight of a small group of patients with haemophilia, who, through no fault of their own, have been infected with the virus (HIV) which causes Acquired Immune Deficiency Syndrome (AIDS). This they have received from imported and home prepared plasma concentrates which were used to treat their bleeding episodes.

We now have good evidence that about 30 per cent of all our patients, so far tested, have been infected by this virus and if one looks only at severely affected patients this rises to 70 per cent in most Centres in the United Kingdom. In addition, to date, we have 29 patients who have developed the clinical disease of AIDS of whom 23 have died. Also, 23 patients have the lesser disease of AIDS-related complex and 109 (13%) have other clinical manifestations.

I believe that this tragedy which now affects 20,000 haemophiliacs internationally represents one of the greatest medical catastrophies ever and makes the saga of thalidomide and 'Opren' pale into insignificance.

It is clear that we are only now seeing the death rate start on its upwards spiral and the number of clinical syndromes rapidly ascalate. It is, however, those haemophiliacs who now carry the virus that our hearts must go out. The number is about 1,000 in the U.K. Their whole lives lie in ruins. They cannot get Insurance, they therefore cannot get a mortgage; schooling, employment and social relations have major problems. The whole family unit is under stress with the dawning realisation that wives may be infected (about 2-5 per cent) and they, in turn, may affect the baby in the womb.

I believe most patients and their families, despite the bitterness and anger, realise that it is unlikely that legal recourse will be of value. I wonder if your Government would, therefore, like to explore the possibility of some form of "No-fault" compensation scheme, which would go some way to ameliorate the plight of this most unfortunate group of patients.

Yours sincerely,

GRO-C

Dr. C.D. Forbes, D.Sc., M.D., F.R.C.P.,

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