

HAEMOPHILIA CENTRE & HAEMOSTASIS UNIT

Director : Professor Christine A Lee MA MD DSc(Med) FRCP FRCPath
Consultant : Dr Simon A Brown MD MRCP MRCPath
Senior Lecturer : Dr David J Perry MD PhD FRCP FRCPath
Associate Specialist : Dr Thynn Thynn Yee MSc MD MRCP
 Tel: +44 (0) 207 472 6630 Fax: +44 (0) 207 830 2178 Email: GRO-C

Royal Free Hospital
 Pond Street
 London NW3 2QG

Tel 020 7794 0500
 Fax 020 7830 2468

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 20th May 2004

Professor Frank Hill
 Chairman, UKHCDO
 Department of Clinical & Laboratory Haematology
 The Birmingham Children's Hospital
 Steelhouse Lane
 Birmingham B4 6NH

First Class Mail + E-Mail

frank.hill@

GRO-C

RECEIVED

26 MAY 2004

HAEM. SECS.

Dear Frank

I wrote to you on 8th April and I want to commit to the record the concerns that I continue to have following the meeting on 12th May to discuss vCJD in the context of haemophilia.

There are clearly three areas of concern : the public health strategy; the information to be given to patients; and the protection of the treaters, namely the doctors.

Clearly we will need to follow the guidance of the vCJD incidents panel regarding our patients and high risk procedures such as brain surgery, tonsillectomy, ?endoscopy etc. It is imperative, however, that our patients are treated as a 'whole' and a blanket strategy developed. Individual risk assessments may be made and follow on as part of a research study. However, at the present time such information is essentially meaningless to the individual patient. The haemophilia community should lead in the development of information and the delivery of that information to patients.

With regard to information to be given to individual patients, haemophilia Directors should be provided without any further delay details of the additional 'implicated' batches of concentrate. We have already engaged our patients about this issue, specifically in 1997 and 2000 when they were able to know the 'implicated' batched they received.

It is important that the protection of the treating doctors is not overlooked. There are currently several doctors under investigation by the General Medical Council because of the way patients were or were not informed about hepatitis C. I have personally been involved in defence of doctors wrongly accused of transmitting HIV – notably Professor Jean Pierre Allain who was imprisoned for two years and Professor Temperley in Ireland (the Lindsay enquiry).

INTERNATIONAL TRAINING CENTRE OF THE WORLD FEDERATION OF HAEMOPHILIA



Royal Free Hampstead NHS Trust Royal Free Hospital, Pond Street, London NW3 2QG Tel 020 7794 0500 Fax 020 7830 2468
 Pamela J Chesters, chair Martin Else, chief executive
<http://www.royalfree.nhs.uk>

It is frankly scandalous that we are denied the opportunity of conveying full information to our patients. Our doctor-patient relationship is in danger of being destroyed because implicated batch numbers are being withheld. It is not clear if this is the Health Protection Agency, the vCJD incidents panel or the Department of Health.

The duties of doctors registered with the General Medical Council include :

- 'making the care of the patient their first concern'
- 'giving patients information in a way they can understand'
- 'respecting the right of patients to be fully involved in decisions about their care'

I would suggest that at the present time we are failing in our duty of care for matters out of our control.

Yours sincerely,

GRO-C

Professor Christine A Lee

Enc.

cc

Dr Noel Gill, Health Protection Agency, CDSC Colindale

Professor Don Jeffries, vCJD Incidents Panel, C/o Dept of Virology, St Bartholomew's Hospital

Dr Patricia Hewitt, Lead Consultant in Transfusion Microbiology, NLBTU