F

Mann Pat RQ3) BCH

To: Eddie Owens
Subject: Letter from UKHCDO

Dear Mr. Owens,

I attach a letter from Dr. Hill.

Regards,

Pat Mann
(Dr. Hill's Secretary)

UKHCDO - Letter
26.04.2002.doc...

UKHCDO

United Kingdom Haemophilia Centre Doctors' Organisation

Our ref: FGHH/PAM 26 April 2002

Email to:
Eddie Owens
Aventis Baring.

Dear Eddie,

The UKHCDO is a registered charity. The object of this charity is:-

(1) To preserve, protect and relieve persons suffering from haemophilia and other inherited bleeding disorders.
(2) To advance the education of the medical profession, the nursing profession and the general public in the knowledge of haemophilia and other inherited bleeding disorders and their treatment.
(3) To promote or assist in the promotion of research into the causes, prevention, alleviation and management of haemophilia and other inherited bleeding disorders and to disseminate the useful results of such research.

The UKHCDO database located at the Oxford Haemophilia Centre has contributed significantly to raising standards of care for patients with bleeding disorders over the years. The Alliance and the Commission of Specification for Haemophilia have recognised this and have placed the UK database central in service provision. The UKHCDO has recognised that if the database is to be used optimally for this purpose, then it is essential that data collection and collation of data must be changed so that we have current data available in year. To this end Charles Hay, in his capacity as Chairman of the UKHCDO Information Technology Working Party, has undertaken a detailed assessment of the central database. In addition, he has addressed the issue of developing software for Centre databases to provide information that can be immediately available to the Centre, local commissioners in the form of agreed reports and easily sent online to the central database to provide current national data. This programme is now being tested in pilot Centres and implemented for others in the coming year. The issues of security and compliance with data protection have also been fully considered.

The UKHCDO applied for a NHS Section 64 grant to begin this work but was unsuccessful, but fortunately we received an unconditional grant from Wyeth Genetics, which has allowed us to begin this task. With the changing patterns of contracting in the NHS and many of the new commissioners not yet set up, it is proving difficult for us to establish a steady funding stream for this enterprise. Funding is also required for the UKHCDO Secretariat and maintenance,

cont'd...

trouble-shooting and further development of the Centre and national computer network. Given the issues facing haemophilia care, we feel we must press on rapidly with these software developments. The issues with the funding of the Secretariat are brought into sharp focus by the imminent retirement of Rosemary Spooner in June of this year. Rosemary has been employed by the Oxford Health Authority, but UKHCDO is anxious to move away from the grace and favour arrangement to one where we are able to control and determine the size of the Secretariat to not only maintain and develop the database, but to use this valuable resource for research to the benefit of the patients.

As a registered charity the UKHCDO is restricted from trading and while we may need to develop a trading arm for the future, this will take time and cause inevitable delays at a crucial time when we need the "all singing, all dancing" database. Although we have opened discussions with the Department of Health on these issues, we are not able to predict outcomes or time scales with regard to them funding these activities.

As a charity we are able to accept donations. Knowing how supportive the pharmaceutical industry has been to various aspects and organisations involved in haemophilia care over the years, I am writing to ask whether your organisation would consider making an unrestricted (unconditional) grant to the UKHCDO. This would allow us to update the national database and roll out the Centre databases to as many Centres as possible as quickly as possible. In order to achieve this we estimate that we require of the order of £160,000 per annum for the next 2 years, while we pursue and establish a more permanent funding stream from NHS sources.

As an Organisation we wish to rise to the challenges facing haemophilia care and to be able to provide leadership in taking the issues forward with all partners in haemophilia care. Accurate and current data will be essential in this task. We hope you will consider the contents of this letter carefully. If you would wish to discuss things further with me, then I would be happy to be contacted by telephone or email. We hope you will be able to support us in our venture.

If possible I would very much appreciate an indication, before the next Advisory Committee meeting on 10 May, as to whether your organisation will be able to support UKHCDO as set out.

With kind regards,

Yours sincerely,

Dr. F.G.H. Hill
<u>Chairman – UKHCDO (on behalf of UKHCDO)</u>

Please reply to:
Dr. F.G.H. Hill, Chairman–UKHCDO, Department of Clinical & Laboratory Haematology,
Birmingham Children's Hospital NHS Trust, Steelhouse Lane, Birmingham B4 6NH.