

Rev Alan Tanner
The Haemophilia Society
123, Westminster Bridge Rd,
London, SE1 7HR

GRO-A

COPIES TO---
Graham Barker,
Simon Taylor.

22/11/94

Dear Alan

May I first start by thanking you and the Society, for a really wonderful weekend at Coventry.

However I'm writing to you now in my own right, and not as a member of the Manor House Group, and I write in anger and also sadness. As I'm sure you seen for yourself at the DROP IN MEETING, at Coventry, on Hepatitis, the amount of anger and frustration which was running very high at the meeting, anger and frustration which I myself feel.

I feel that the Society is its own worse enemy, and unless the Society changes its ways DRASTICALLY, its going to open a PANDORA'S BOX. As I'm sure you are well aware over the last five years, I have been bombarding the Society constantly with letters, with regards, help and support for people with HEPATITS, only to be told, and made to feel that I was the only person in the Society, that seemed to be having problems. You can imagine how upset and angry I was, after talking to other members at the DROP IN GROUP, only to find out that I was far from being on my own. I was even more hurt and upset, when it was brought to my attention that several other members were also told by the Society, *ie.* that they were the only ones having problems. This I find to be, totally unacceptable. This is the sort of behaviour you would expect from Health Authoritys and the Government, not by a Society that claims to represent people with HAEMOPHILIA, and who's motto is "CARING FOR PEOPLE WITH HAEMOPHILIA".

Another serious point I would like to emphasise, is with regard to, CENTRE DIRECTORS, and LIVER SPECIALISTS, with holding information from the patient, regarding his/her illness, from Hepatitis. I myself know of several cases where the patient only found out long after the doctors knew of their infection, in some cases years after. In one case the patient only found out when he was informed by the doctor, he did not have long to live, even though his doctor knew he had been infected for FOUR YEARS. This is a disgrace, and is one area where the Society can and should do something to remedy this appauling situation.

I sincerely hope and pray, that the anger and frustration of the membership of the Society, has been recognised by the Society, and that lesson's have been truly learnt and the Society can now be of more help to its people.

GOD BLESS

Yours Sincerely
Alan Tanner

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