Sick Bay

HAMPSHIRE AREA HEALTH AUTHORITY (TEACHING)

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AA/SAN

14th November 1978.

Professor H. A. Lee,
Consultant Physician,
St. Mary's Hospital,
Portsmouth.

Dear Professor Lee,

re: GRO-A 59

John O'Brien has passed your comments about GRO-A on to me. I am a little suprised that you have not written to me direct as an interchange of views might have clarified the position a lot earlier. Your comments raise several important matters and I would like to answer in depth.

a) I undertake the clinical responsibility for 55 of Britain's severest haemophiliacs for thirty-six weeks of the year. There is no way that I would be prepared to take on this commitment without the freedom to make my own clinical decisions. Your Registrar who telephoned me last week to complain about GRO-A not being on prophylaxis, mentioned that he had spoken to someone in July. I asked him who he had spoken to and his reply was that he was not sure but he "thought it was a technician". This is an astonishing method of discussing a medical problem and makes me feel that perhaps the word 'discussion' is out of place. He may have assumed that he was giving us instructions as how to manage the case.

I should point out that my patients come from many sources, and have been managed in many different ways-some good, and some bad. I try to have a consistent approach to treatment here, which means that I occasionally use a different approach to that of the Home Centre.

b) As far as prophylaxis itself goes, I am well aware of its potential for reducing the frequency of bleeding episodes, having published two controlled trials from this Centre. What I am also becoming increasingly aware of, is the potential danger to our haemophiliac population of hyper-transfusion with blood products. Over the past year only 12 of our 55

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boys had liver function tests which remained normal. Several authorities have recently reported increased incidences of chronic aggressive hepatitis. There is also accumulating evidence that the haemophiliac population has a higher blood pressure than the normal population and our observations here suggest that this may also be related to frequency of transfusions, ( GRO-A incidentally, currently has an S.G.O.T. of 87 and a random blood pressure of 120/80. He is, therefore, a candidate for both complications). I am, therefore, increasingly wary of the indiscriminate use of blood products in our boys. This does not mean that I do not use prophylaxis in certain situations. I believe the clinical indications for prophylaxis are:-

(i) Frequency of bleeding and by this I am talking about 20-30 bleeds/100 days (GRO-A appears to have a bleeding frequency of about 10 bleeds/100 days, while our average bleeding frequency last year was 12.6 bleeds per 100 days).

(ii) The covering of a "bad patch".

(iii) Cover for an extended course of physiotherapy and for invasive procedures.

I do not believe in extended prophylaxis in any other situation.

The situation with GRO-A has several components. Firstly, your letter to me only mentioned that GRO-A had been on prophylaxis. There was no request or suggestion that I should carry on with your management and as said before, I hope you would not imply that I had no clinical freedom in this matter. I repeat that the way your Registrar communicated this wish to my Centre was highly likely not to produce a result. The message never got through to me and I am not suprised as I would imagine that any technician would expect medical decisions or discussions to be between medical staff. An analogous situation might be were I to ring one of the technicians in the dialysis unit with instructions as to how I wanted a referred patient of mine to be handled in your unit.

c) Available resources of Factor VIII. This country is not sufficient in Factor VIII and, even if I believed that prophylaxis was always the right management for all haemophiliacs, we are still in the position of rationing this form of treatment. It is up to all of us to allocate resources responsibly and as we see fit. The rationing of dialysis is not something that I would wish to influence you on, and I am in no doubt that you would allocate your resources as you saw fit irrespective of the referring doctor's wishes.



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d) The influence of different environments. The situation at Treloar College currently is that treatment is immediately available and our boys are almost bullied into the early reporting of bleeds. Consequently, they lose minimal time from school compared to the situation you quote, where it appears GRO-A needs to be admitted for almost every bleed. He has, so far, only spent one day in our Sick Bay. Further, he has had more intensive physiotherapy and attention to his locomotor function than at anytime in his life. I believe that his wasted quadriceps are compounding his problems, and I have put him on a programme of graded exercises. We are also, as you know, embarking on a major enterprise with him attempting to teach him to infuse himself. The problems, you will understand, are considerable, but we are making some headway and I believe that he is deriving enormous benefit from our attention.

I took all the above considerations into account when I made what you call "a grave error of judgement". (It has been a long time since I have heard this sort of description of another colleagues actions). Perhaps you might now like to reconsider that statement.

Finally, I am not clear what I am accused of undoing - from our extensive experience of prophylaxis, I can assure you that unless combined with an active course of physiotherapy, prophylaxis does not improve either joint function or the underlying bleeding frequency.

Yours sincerely,

GRO-C

A. Aronstam
Consultant Haematologist.

C.c. Dr. J. O'Brien