Mr Hamill
I've minuted. The ¼ly steps seem a good idea. GRO-C

Mr Macniven,
Please return this with any views on the desirability/practicability of the ¼ly meeting suggestion. The "politics" of this baffle me GRO-C 29/8

Dr Scott
Mr Hamill
Mr Calder
Mr Macniven
Dr McIntyre
Mr Panton

FACTOR VIII USE AND REQUIREMENTS IN GLASGOW

The long-awaited meeting with Glasgow Haemophilia Directors took place on 25 August. Mr Panton and I met Dr George McDonald and Dr Lowe (from Glasgow RI) and Dr Brenda Gibson (Yorkhill). Dr Ruthven Mitchell (Regional Transfusion Director, West of Scotland BTS) was also present.

We were immediately provided with a detailed and comprehensive statement which is attached, and carries one or two explanatory notes of my own, in square brackets.

The following points emerged from the statement and related discussion:

* Self-sufficiency for Factor VIII has been lost, after being achieved 4 or 5 years ago; during 1985-87, Glasgow bought in no commercial factor VIII, but now Glasgow has concluded a contract for 100,000 units of a commercial product per month, at a cost of about £23,000 per month. Edinburgh is believed to have made a similar arrangement. We were told there was no difficulty in striking a deal, but commercial supplies may soon diminish.

* The role of surgical operations is clearly great: 4 patients undergoing operation consumed about half as much factor VIII as all the rest (about 100) together in the first half of 1988.

* Glasgow's consumption of factor VIII per patient treated is in general a little below the UK average. Edinburgh is rather higher than the average.

* Glasgow has taken a number of steps, listed on p. 3, to curb consumption, and predicts that the full year use for 1988 may be no greater than in recent years. The logging of consumption by individual patients sounds thorough and should be (I asked) enough to prevent outright theft too. There is no question whatever of dosage having got out of clinical control.

* Our interpretation of the trends should not rest content with this optimistic prediction, which is made during the maintenance of specific curbs on demand. The underlying trend of demand is upward (top row of figures in p. 1 of statement). It is upward because adequate treatment with increasingly pure and safe preparations prevents the destruction of joints that cripples patients, and thus creates an obvious burden on the orthopaedic and other NHS services. We could in principle forever restrict demand at an even lower level than now, but the penalties are severe, and present-day patients carry the consequences of insufficient therapy

of years ago. On the other hand, the 75 patients in all Scotland unfortunately infected with HIV will presumably not require factor VIII over a long lifespan, although there are difficulties in predicting their futures. Meantime the infected patients tend to be unusually heavy users of factor VIII, because (Dr Lowe) they never feel well, feel worse than others when they bleed, and seek more therapy for this reason.

* Glasgow have arranged to route Scottish factor VIII preferentially to Yorkhill, to meet the children's needs. Consequently the cost of the commercial purchases falls upon the budget of the RI Haematology Department, even for treatment of patients residing beyond GGHB's area. I requested that this question should be pursued through Mr Peterken, but also undertook to make known here the strong feeling of the Glasgow Haemophilia Directors that the cost is due to PFC's inability to make enough factor VIII, and should either be a matter for a special allocation, or be charged to CSA.

* Production and consumption of factor VIII have up to now been reviewed annually at a meeting convened by SHHD and chaired by myself. The meeting has also served to ventilate other long-term problems, such as licensing and compensation. It has received and considered a document from SNBTS, but none from the Haemophilia Directors, who were in the past regarded as reluctant to release their data, in particular on their use (if any) of commercial products. This arrangement is now manifestly inadequate. The Glasgow Director pointed out that much more frequent liaison was needed to match supply and demand properly - monthly maybe, certainly quarterly. In principle, the Department need not be involved at all. In practice, relations between SNBTS and its factor VIII "customers" have apparently required the Department to act as broker.

There is not an administrative vacuum to fill, because I strongly suspect that Dr Ludlam is in process of convening a group on his own initiative. The suggestion I bequeath is this: we should lean on CSA as supplier to convene a meeting at least quarterly, comprising representation of SNBTS, PFC and Haemophilia Directors, the meeting to review supply and demand for factor VIII (& anything else used by the Haemophilia Directors more or less exclusively) and to report to the subsequent meeting of the BTS Sub-Committee. In this way SHHD would remain informed, and so would the BTS Sub-Committee, who (be it noted) have seen what Professor Cash put to the May meeting of Haemophilia Directors, but have not made any arrangement to see the minute of that meeting, which is now really beyond challenge!

* It is, as ever, important to bear in mind that SNBTS produce many products, of which FVIII is only one.

* I have now long sought from Mr Donald factual data about Glasgow's (along with everyone else's) commercial purchases of FVIII, up to this April and later, if possible. We now have these data. But they have never come from Mr Donald; instead, he sends views from Glasgow and elsewhere on the general issues. Clearly

this channel does not work in the long run. It may be that Dr Davidson or someone else in Glasgow vetoes release of the facts. Mr Clyde, by arrangement with Mr Calder, gathered all the data most successfully two years ago. Experience suggests to me that this information, politically quite warm, should again be gathered annually through Mr Calder, but with the express authority of GMs, which appears to be needed to override local vetoes. The alternative is to rely on a quarterly meeting convened by CSA to produce the information. It might work ...

GRO-C

pp DR JOHN FORRESTER
Room 25
St Andrew's House

26 August 1988