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Exploratory Meeting of Blood Transfusion Directors and Haemophilia Reference Centre Directors, etc. in Sheffield at the Blood Transfusion Centre.

Minutes of the meeting held on Friday, 22nd October, 1976 at 9.30 a.m.

1. Apologies for absence - Major-General H.C. Jeffrey (Edinburgh)
Dr. D. S. Smith (Wessex)
Dr. F. Stratton (Manchester) represented by Dr. Wensley at the meeting

2. Present - Dr. Rosemary Biggs ) Joint Chairmen
Prof. E. K. Blackburn )

Dr. L.A.D. Tovey
Dr. J. Darnborough
Dr. G.H. Tovey
Dr. G.W.G. Bird
Dr. D. Lehane
Dr. D. Lee
Dr. H.H. Gunson
Dr. T.E. Cleghorn
Dr. D. Ellis
Dr. W. J. Jenkins
Dr. J. Blagdon
Dr. K.M. Dormandy
Prof. G.I.C.Ingram
Dr. S.H.Davies
Dr. H.T. Swan
Dr. F.E. Preston
Dr. J.S. Lilleyman
Dr. K.L.Rogers
Dr. Sheilagh Murray
Dr. J. Wallace
Dr. W. Wagstaff
Dr. Wensley
Dr. B. Bevan
Dr. J.D. Cash
Mr. John Watt
Dr. E. Bidwell
Dr. W. D'A. Maycock
Dr. C.R.Rizza
Dr. A.L. Bloom
Dr. I.W. Delamore
Dr. P. Jones
Dr. C.R.M. Prentice
Dr. G.A. McDonald

3. Professor Blackburn stressed the informality of the meeting. Only Haemophilia Reference Centre Directors and the Blood Transfusion Directors related to the Reference Centres along with Fractionation Experts had been invited. Representatives from the D.H.S.S., Welsh Office, Northern Ireland Health Authority and the Scottish Home and Health Department had not been invited at this stage.

Reason for calling the meeting

At the Second Meeting of the Haemophilia Reference Centre Directors in Oxford on 29th June, 1976, Professor Blackburn was requested to organise the present meeting. The Reference Centre Directors believe that the Haemophilia Centre Directors in toto are able to offer much assistance in expediting the adequate production of Factor VIII concentrate in the United Kingdom by the Blood Transfusion Centres, e.g. by outlining the amount of cryoprecipitate needed or not needed, and by purchasing Factor VIII concentrate from abroad for a set period of time to allow increased plasma availability for fractionation. The view of the Haemophilia Reference Centre Directors is that there should be no need to import expensive Factor VIII concentrate from abroad.

4. Item 3 of the Agenda read "There is the need for at least 40,000,000 units of freeze-dried Factor VIII to treat the haemophilic population of the United Kingdom. Is this estimate correct?". Dr. Biggs and Professor Blackburn had based this somewhat provocative question on published data.
Dr. Biggs presented data as follows: Since the introduction of commercial Factor VIII, there had been a steady increase since 1973 in the usage of Factor VIII concentrate probably due to both the patients and the Haemophilia Reference Centre Directors becoming aware of the commercial preparations. It was agreed that estimates are bound to be minimal and that they are likely to be superseded.

From data collected in eight countries up to 1975, the average use of Factor VIII was 11,058 units per patient per year. The average assessed incidence of haemophilia in these countries was 6.5 per 100,000 of the population. Translated for the United Kingdom this implies the use of:-

For England, Wales and Northern Ireland - 36,481,890 units
For Scotland - 3,741,917 units
40,223,807 units of Factor VIII per year

These data agree fairly well with predictions made by Dr. Biggs and colleagues for the United Kingdom.

A proportion of haemophiliacs are treated in hospitals which are not Haemophilia Centres. Steps are being taken to determine the proportion.

Of the Factor VIII needed to treat haemophiliacs in the United Kingdom at least 24 million units is required in the freeze-dried form for safe protection of operation cases and for safe home therapy. There is urgent need to convert as much as possible plasma at present used for cryoprecipitate to a freeze-dried preparation.

Five commercial companies are licensed and supplying very satisfactory Factor VIII in the United Kingdom and it will be surprising if doctors and patients do not come to prefer these very convenient preparations as compared with cryoprecipitate.

Discussion proceeded as follows:

Dr. Davies - It is important to bear in mind that there are many other valuable products besides Factor VIII concentrate available during its production.
Dr. Biggs - In the territory supervised by Oxford approximately one million units of Factor VIII was used in 1974 and 2.2 million units in 1975. We have every reason to believe that the usage will be substantially higher in 1976. There has furthermore been no fall-off in usage of cryoprecipitate in the territory. In Dr. Biggs' view the figure of 40 million units of Factor VIII concentrate is less than realistic.
Dr. Cash - He agreed with Dr. Biggs' last remark. He recommended a firm planning decision re cryoprecipitate and/or concentrate, otherwise we would continue to float on a mattress of complete uncertainty. Dr. Cash pointed out that haemophiliacs are now covered for ski-ing and other relatively violent pursuits. He was alarmed by these sporting activities. He felt that the relatively large amounts of Factor VIII required are morally wrong. Dr. Cash believes that our total objective should be to make available to haemophiliacs a completely normal sedentary life. From the transfusion aspect it is best to have a target nearer to reality over a five-year plan. Regional planning is needed.
Dr. Cash had recently had three patients properly requiring large amounts of Factor VIII in emergency and he recommended for this purpose 25% of our total target.
Dr. Davies - Unless we have a policy we all agree, our target figure will reach higher and higher.
Dr. Wallace - Scots taking charge of the meeting! At a recent meeting of the Directors of Haemophilia Centres and the Transfusion Directors in St. Andrew's House it was noted that so far as St. Andrew's House is concerned they are desperately anxious for an agreed policy in the U.K. He supported Dr. Cash re a target. While some thought that 40 million units per annum is a realistic target at present, what is worrying is escalating demands. We now have many young haemophiliacs who will need more Factor VIII, and ageing haemophiliacs developing malignancies need more Factor VIII. For these reasons his group feel that haemophiliac should live within the limits of their disabilities. Dr. Wallace said that the St. Andrew's House Group were thinking of having a joint discussion with the Haemophilia Society as they realise these problems of escalating demands within the N.H.S. If we in England can agree on a policy and fit in with Scottish ideas it would be a great help.
Dr. Jones - He suggested 42.4 million units per year for 1975. Dr. Jones

estimated that the number of haemophiliacs who take risks is about 1%. Normal football and swimming etc. are encouraged. If haemophiliacs sit around in sedentary occupations they will need more Factor VIII. Some patients told to lead sedentary lives have taken risks in private.
Dr. Cash - He pointed out why we should not live above our means.
Dr. Davies - Supported Dr. Cash.
Mr. Watt - He had discussed with Major-General Jeffrey the production unit at Liberton. Mr. Watt believed that the crux of the whole matter to be inadequacy of current information. He disagreed with Dr. Biggs in that we need accurate data for long periods of time. We need to know what patients X, Y and Z need to have every week and every month.
Dr. Biggs - Figures are an average of the use on patients. These figures are derived from patients' records.

Further discussions on similar lines took place between Mr. Watt, Dr. Bidwell, Dr. Cash, Dr. Biggs and Professor Blackburn.

Dr. Prentice - Dr. Biggs has produced very reasonable figures for the country. How do we get a target of 40 million?

Out of further discussion between Mr. Watt and Dr. Maycock, the following main points arose:

Dr. Maycock - One cannot have an open-ended target - there must be a target for a period of ten years. It takes a long time to develop a transfusion service. Since a group of experts advised the D.H.S.S. in 1973, the target has multiplied over three times. It is physically, impossible for transfusion centres to go on at that rate. The users should try to devise a primary target, say for the next ten years and they should take into account the growing ageing population, production etc.
Dr. Cash - Peter Jones' figure of 42 million will let in the commercial units for at least 10 million units. 50 million units is an absolute basic figure, if 25% short. He agreed with Dr. Maycock's view of planning for 10 years.
Drs. Dormandy, Rogers, Davies and Prof. Bloom - queried the type of cryo-precipitate, Factor VIII concentrate and the question of plasmaphoresis.
Dr. Gunson - It is too early to report fully on the findings of the Cryoprecipitate Working Party.
Dr. Jenkins - He reminded the meeting of Dr. Cleghorn's past proposal. If they could obtain an agreed policy with clinical colleagues, from about two million donations they could produce apparently more than the generous targets mentioned so far. The important issue is the capacity of fractionation units to deal with that plasma.
Dr. Tovey - We do not really have a tremendous difficulty in reaching the target. It is not a problem of collection, but of manufacture.
Prof. Blackburn - Item 3 of the Agenda - do you agree with the present target?
Dr. Tovey - We think that we can get near that figure. The changeover has not been grossly dramatic.
Dr. Bevan - She pointed out the difficulty in obtaining money to provide necessary equipment and staff.
Prof. Bloom - We use cryoprecipitate for ordinary bleeds, e.g. into joints, but we need for treatment of inhibitors and home treatment freeze-dried material.
Dr. Wagstaff - Over the past 12 months in the Trent Region we have averaged just about 10,000 units per patient. This compares very well with Dr. Biggs' figure of 11,000. In this Regional we can cope, but with routine hospital out-patients being treated with cryoprecipitate.
Prof. Ingram - We should be able to use Factor VIII concentrate for all our patients.
Dr. Tovey - Is it possible to manufacture 40 million units if we collect the necessary plasma?
Prof. Blackburn - Do the Scots supply Factor VIII to Peter Jones (North of England)?
Dr. Jones - Only special material from Edinburgh.
Dr. McDonald - Many Haemophilia Centre Directors are reluctant to give up the usage of cryoprecipitate until they can be assured that the concentrate will be available.

Dr. Bidwell - We are faced with strong commercial interests showing films to the patients etc. This is totally immoral.
Prof. Bloom - N.H.S. material compared very well with commercial products.
Dr. Jenkins - Can we ask the representatives from the production units what the maximum capacity is without further expenditure? How many million units could they produce?
Dr. Maycock - They are pretty well at the top of their capacity. The D.H.S.S. knows that something has to be done.
Dr. Jenkins - Can they deal with 40 million units?
Dr. Maycock - 15 million units - Oxford and Elstree - unless recovery is greatly increased.
Mr. Watt - Presently they make 12 to 13 million units. With capital investment of £20,000 they could increase the output to 24 million units of Factor VIII per annum, given plasma as it is needed. In the changeover from cryoprecipitate to concentrate a dead time of three months would be needed in Scotland, and a longer period of time in England.
Dr. Prentice - If Mr. Watt received an extra £25,000, his capacity could reach 20 million units, giving for the U.K. a total of 35 million units.
Prof. Blackburn - It seems that sufficient plasma can be obtained from donors, and that the real difficulty relates to staffing, premises and equipment for preparing the concentrate.
Mr. Watt - His centre is clearly not working to full capacity.
Dr. Maycock - Of the original target in 1973, three transfusion centres have taken three years to provide the necessary plasma.
Dr. Bidwell - we could double Factor VIII concentrate if we received the necessary plasma.
Mr. Watt - Of 40 million units required in England and Wales, something like 30 million units is now available as cryoprecipitate.
Prof. Bloom - Re home treatment, he pointed out that while 50 ml. volume seems to work, 15 ml. volume is better.
Dr. Wallace - The Transfusion Service is perfectly capable of looking at problems and trying to find a solution.
Dr. Biggs - We are spending millions of pound on commercial Factor VIII. Building up supplies of N.H.S. concentrate would reduce the bill for commercial concentrate in this country. If there is nothing else available, Haemophilia Centre Directors are forced into arranging for its purchase.
Dr. McDonald - He reminded us that four years ago the proposal that a proportion of commercial concentrate should be purchased in order to give Mr. Watt time to build up a stock of concentrate. This idea was turned down 100% by administrators.
Mr. Watt - The ability of the haemophilia fraternity to prognosticate their need is not half that efficient - that is the real problem.
Prof. Blackburn - While I have much sympathy with your view, the fraternity do have a pretty good idea of what they need.
Dr. Maycock - Re the target of 40 million units, the clinical side should try to build in how much cryoprecipitate is presently used and how it will continue.
Dr. Prentice - To supply the U.K. with commercial concentrate for three months - this would be a once and for all hopeful expenditure of about one million pounds.
Dr. Jones - With Dr. Murray's capacity if they phased out cryoprecipitate completely, they would be one million units of Factor VIII short per annum in the Northern region.
Dr. Wagstaff - One million pounds represents three months' supply of Factor VIII.
Dr. Jenkins - Target - Haemophilia Centre Directors - how much freeze-dried and how much cryoprecipitate?
Prof. Bloom - 100% freeze-dried.
Dr. Bevan - We should be able to phase out cryoprecipitate in three years and to replace it with freeze-dried Factor VIII.
Dr. Prentice - I suggest that presently the target of the Haemophilia Centre Directors is 40 million units of concentrate, rising to 50 million units in the next three years.

The discussion so far had taken in items 3 to 5 on the published Agenda.

Dr. Maycock - We ought to take item 6 ondistribution. It has been officially

decided to distribute the main material in proportion to the number of haemophiliacs treated in the various Regions. The material has been sent to Reference Centre Directors and Regional Transfusion Directors and they will arrange internal details.
Dr. Wensley - In Manchester all Factor VIII containing materials are distributed by the Transfusion Centre, including the commercial material.
Dr. Prentice - Objection. Manchester money comes from the Region and not from the District.
Dr. Lehane - Our District purchase is 60,000 units of concentrate.
Dr. Tovey - Define the role of the Regional Transfusion Director
Prof. Blackburn - Since June, 1976 I have been trying to call a meeting of the Trent and Yorkshire areas.
Dr. McDonald - We have the finest Blood Transfusion Service in the world and we are most grateful for the excellent service which Blood Transfusion Directors provide for us. The problem discussed is not confined to haemophilia only. Only by discussion will we find a solution.
Prof. Blackburn - We are most grateful for the kind hospitality of Dr. Wagstaff and Dr. James and of their staffs. It was agreed that a suitable letter of appreciation should be forwarded, also including the excellent service of Miss May Smith in recording the Minutes of the meeting.

The meeting closed at 1.00 p.m.
No further meeting was arranged.