



The Haemophilia Society

123 Westminster Bridge Road
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Patron, HRH The Duchess of Kent

President:

R. G. Macfarlane, CBE, MA, MD, FRCP, FRS

Chairman:

The Revd. A. J. Tanner, MA

General Secretary:

David G. Watters, JP

Member of the World Federation of Hemophilia

Please reply to:—

MINUTES OF AGM OF LEWISHAM GROUP HELD IN MEDICAL CENTRE LEWISHAM HOSPITAL
15th April 1988 at 7.30pm

GRO-A in the chair and 26 other people present.

Apologies from **GRO-A**.

THE MINUTES of the previous AGM had been circulated and were signed as a true record.

There were no matters arising which were not covered by agenda.

SECRETARY'S REPORT was presented by **GRO-A** on behalf of **GRO-A**

Caravan - disposed of due to old age, the site owner had refunded the rental and paid us for it. It served the group and Society well over the last 13 years.

The Haemophilia Centre at Lewisham Hospital has been recently moved and updated and was refurnished with a grant of £1500 from the Haemophilia Society.

Fund raising has continued as usual although we had no stall at Blackheath in '87. Tombola and Bric-a-brac are planned for Blackheath '88. A new venture was the successful sale of Christmas goods in out-patients hall prior to Christmas.

The Seminar in Liverpool had been attended by **GRO-A**

GRO-A and **GRO-A**

The campaign for recompense - **GRO-A** and other members had written to their M.P.s and the campaign had been handled well by the Haemophilia Society.

TREASURER'S REPORT Excess of Income over Expenditure during the year amounted to £684, this, together with amounts brought forward gives a bank balance of £1222. During the evening, **GRO-A** presented the Rev. Alan Tanner, chairman of the Haemophilia Society and our speaker for the evening, with a cheque for £1000. Thanks were given to Mr. Swales, our auditor, who,

for twenty years has audited the books free of charge.

The adoption of the accounts was proposed by Mr. **GRO-A**, seconded by Mr. **GRO-A**.
GRO-A proposed a vote of thanks to the treasurer.

ELECTION OF OFFICERS AND COMMITTEE - the present officers and committee were re-elected en bloc, with the addition of Mrs. **GRO-A** proposed by Mrs **GRO-A** seconded by Mr. **GRO-A**

AOB - **GRO-A** introduced the Rev. Alan Tanner as our guest speaker. The Rev. Tanner outlined his interest in haemophilia **GRO-A** how it affects the **GRO-A** and how treatment has progressed over the years. New problems had arisen with the advent of HIV/AIDS and all Concentrates are now heat treated to prevent further infection. Unfortunately many haemophiliacs are already affected and many distressing situations have arisen. The Society had responded speedily to Press reports by producing HAEMOFAC at regular intervals to keep members informed. Many of those infected had considered legal action and some are in the process of doing so. This has to be done by individuals and cannot be done corporately by the Society. With regard to recompense, members wrote to their MPs and the Executive Committee had meetings with the Secretary of State. Many MPs were moved by the situation in which haemophiliacs found themselves with the result that an allocation of £10,000,000 recompense was made as an ex gratia payment in recognition of very special circumstances. A Trust Fund, the 'MacFarlane Trust' has now been established to administer the fund. The Trust has six trustees nominated by the Haemophilia Society, and four nominated by the Secretary of State. So far, the Trust have met twice, they are quite separate from the Executive Committee of the Society, the Case Committee will continue as before. It is not possible to divide the amount up equally, funds will be allocated in cases of individual need and stress. A social worker and committee will consider each case on its merits. The Rev. Tanner went on to mention Life Assurance and Mortgage Protection, it is possible that Trust money could be used but Life Assurance would be costly, this area is not settled yet. Is ten million enough? What is enough? This will allow a start to be made and if not enough, further representations will be made.

GRO-A thanked Rev. Tanner and there were some questions from the floor.

GRO-A briefly reported on the seminar and gave a full copy of her notes to the chairman to send to members.

The chairman welcomed Dawn Lewis from Armour who gave the latest update on monoclate and members were able to ask questions and discuss relevant topics informally.

Meeting closed, for refreshments, at 8.55pm.

.....signed

.....date

AIDS - A STATEMENT FROM THE HAEMOPHILIA SOCIETY

The Haemophilia Society is saddened by the news that GRO-A has died from AIDS. We take this opportunity to extend our sympathy to his parents and family at this difficult time for them.

AIDS is a complicated condition: this is illustrated by the vast amount of money which is currently invested in research into the condition both in this country and throughout the World. AIDS affects many different groups of people throughout our Society, including people with haemophilia. We welcome the significant progress which has been made during the past year in that it now appears certain that the HTLV-III virus is the causative agent and the news that the majority of people with haemophilia have established antibodies to HTLV-III.

We urge those concerned to proceed with urgency to establish the test for the HTLV-III virus, so that the blood products used by people with haemophilia may be safe as possible. We urge the Blood Transfusion Service to take all possible steps to ensure that blood donations are not received from persons in the risk groups. We have evidence that not all Centres maintain the standards which we would regard as acceptable.

We invite the Government to give urgent consideration to the value of the heat-treated product now available from the United States where extensive research has shown that the HTLV-III virus is eliminated by heat treatment.

The Haemophilia Society do not believe that AIDS risk is restricted to imported factor VIII concentrates. In both the recent deaths from AIDS in people with haemophilia the patients had received both UK and imported concentrate.

The Haemophilia Society continues to urge people with haemophilia to continue to use those concentrates which are prescribed for their use by their medical advisors.

We also urge the Government to do all in their power to ensure that Haemophilia Reference Centres are adequately staffed throughout the present situation with both medical and counselling staff.

BACKGROUND

People with haemophilia do not receive blood transfusions - they are infused with concentrates of factor VIII - the clotting agent missing from their blood. Without regular infusions of this concentrate people with haemophilia are exposed to very great risk through untreated bleeding episodes which will dramatically effect their life-style and increase the likelihood of fatal bleeding episodes.