Witness Name: Beverley Tumelty

Statement No: WITN2412008

Exhibits: WITN2412009-WITN2412013

Dated: 26 January 2021

EXHIBIT WITN2412011

Minutes of the South Wales Haemophilia Group Annual General Meeting. 28th October 2000.

Present

Committee:

Gareth Lewis, David Morgan, Jan Wallace, Ian Tumulty, GRO-A David Edwards, Helen Morris, Chris Morris, Pat Meaden, Other members of the Haemophilia Community

Observers:

David Melding(Welsh Assembly) Keith Colthorpe (Vice Chairman Haemophilia Society)

Apologies

Invited Assembly Members had sent apologies. No other apologies were received.

Chairman's Introduction

Vice Chairman David Morgan chaired the meeting. Members and observers were welcomed to the meeting. It was announced that Gareth Lewis had stepped down as Chairman due to personal reasons. The Committee thanked Gareth Lewis for his hard work, dedication and dynamism in leading the group through a difficult time of change.

The achievements of the Group were reported:

- Recombinant clotting factors for all Haemophiliacs in Wales.
- A new Haemophilia Centre in Cardiff, ranked as the 3rd best centre in the UK.
- The newsletter keeping all haemophiliacs and their families in touch with the latest news, events and development in care in South Wales.
- An active social structure organising Children's Christmas Parties, Charity Evening, Summer Bar-b-q and a Summer Outing to Oakwood Park.
- The HCV Campaign. Committee members have met with Welsh Assembly members and lobbied actively for recognition of the plight of infected Haemophiliacs in Wales. At a recent meeting the Group was able to establish the principle that responsibility lies with the Assembly.

The Chairman thanked Jan Wallace for all her hard work during the year. The Chairman also thanked Gareth Lewis, Norman Harris, Haydn Lewis and Pat Meaden for their work on the HCV Campaign.

It was reported that a BBC television program is in production to highlight the HCV campaign. A number of members have been interviewed. CJD has raised the temperature of public opinion regarding a fair hearing and compensation for all haemophiliacs and people with bleeding disorders infected/affected with HCV.

It was noted that at the July open meeting to discuss the way ahead with the HCV campaign not many members attended. The future of the campaign lies with the members and all were encouraged to contribute.

It was reported that many members felt that the concerns expressed in Wales regarding HCV and other issues were not being given sufficient attention by the Trustees and executive of the Haemophilia Society.

A number of questions and comments from the floor were directed via the Chair to the observer from the Haemophilia Society. Keith Colthorpe reported that he would take back to London all the concerns and questions that he had noted at the meeting.

Treasurers Report.

Ian Tumulty presented the Groups accounts from September 1st 1999 until the present. The group had agreed to a donation of £5,500 to the new Haemophilia Centre. Fundraising included a street collection, live band evening and badminton evening. Birchgrove Wales were thanked for providing use of their accommodation and facilities.

The accounts were accepted as accurate.

Discussion was invited on the issue of whether it is in the interests of the South Wales Haemophilia Group to continue as a local group of the Haemophilia Society or to operate as a separate body.

Comments and questions were received from the floor on the issues of:

- Poor communication between the Group and the Trustees of the Haemophilia Society.
- Access to local funds being difficult for local groups.
- The organisation, expertise and efficacy of Groups from the Devolved countries being superior to that in London.
- The reasons why the Society had been forced by the Charities Commission to change Auditors.
- Disappointment at the apparent lack of progress in the National HCV campaign.
- Lack of apparent interest by the Society at Local Groups Forum in fostering interaction between local groups.
- The Society being unable to represent the interests of all Haemophiliacs, hence the need for and phenomenal success of the Birchgrove organisation.
- A concern that the central executive should be working for the regions and not vice-versa.
- Recent correspondence from the Chief Executive that was perceived as attempting to foster division between the South Wales Group and Birchgrove Wales.

The Chairman asked for a vote on the motion, "Should the Group now break away from the Haemophilia Society and operate as an independent organisation?"

For 11 votes Against 3 votes Abstentions 3

The motion was therefore carried.

Members were thanked for the participation. The observer representatives from Welsh Assembly and Haemophilia Society were thanked for their attendance.

There being no other business the meeting was closed.