Witness Name: Gaynor Lewis
Statement No: WITN2368019
Exhibits: WITN2368020-
WITN2368051
Dated: 4 December 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN2368020

What Birchgrove is and is not

A history of Birchgrove is available on our website if you require further information. However, its initial purpose was in providing mutual support and advocacy for haemophiliacs with HIV. This began in South Wales. After successful events for those in the surrounding area, a group decided to organise a conference for all haemophiliacs with HIV in the UK. It was a success and further conferences followed. We produce a newsletter and will send it to individuals and organisations that ask to be on the mailing list. We do not class those people on the mailing list as "members" because they have not asked to join merely receive a magazine. After having opened an office and set up a phone line we receive phone calls in the office from people with concerns in this area. We do not class them as members nor ask them to join, although we will offer them the magazine if they wish it.

We have set up the Woodland Trust as a long term memorial for haemophiliacs with HIV and indeed some people who have commemorated trees for loved ones have specifically asked NOT to receive the magazine as either they are do not feel it is relevant or they do not like it. We do not consider these people members either. Birchgrove is not a mass membership organisation but will advocate on individuals' behalf and through the newsletter, our work in Wales and the conferences we are known and contacted by a large number of HIV+ haemophiliacs. People frequently contact the office concerning decisions made by the MacFarlane Trust and we attempt to advocate and bring forward those views at Partnership Group meetings. Birchgrove was invited onto the old Partnership Group as an agency and not as a group of registrants.

There are Birchgrove groups in various parts of the UK. We have been happy with groups using the name and each one is autonomous. So Birchgrove Wales which is the largest and provides services in Wales has extended its remit to provide services to haemophiliacs infected with HCV only. The Manchester Birchgrove Group meets regularly and is involved in a partnership with BP NorthWest. None of these decisions were sanctioned, condoned or even discussed by the National Committee because Groups have been free to act as they wish. The National Committee has previously been elected at national conferences but has been open to those individuals who wished to be involved.

It is therefore wrong to speak of Birchgrove as though it is a membership organisation with 10, 20 or even 500 paid up members. We advocate on behalf of people and are in touch with a great many. Individuals may feel part of Birchgrove and we are proud when haemophiliacs say so but we do not choose to call them members nor expect any more from them.

Robert James
Chair National Birchgrove

20th October 2000