Witness Name: William Wright Statement No.: WITN2287019

Exhibits: WITN2287020 - WITN2287086

Dated: 15th April 2021

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Caring for people with bleeding disorders

Scottish Groups Forum Meeting > EXAMPLE OF MINUTES

THE
HAEMOPHILIA
SOCIETY
SCOTLAND

Perth Royal Infirmary - 8th April 2000

Present - Representatives from all Scottish Groups except Grampian Group. Please reply to:

Minutes of	meeting held on 5	th February 200	0 were	proposed by	GRO-A	and
seconded by	GRO-A					: : ,
Apologies -	GRO-A	GRO-A	][	GRO	)-A	GRO-A
GRO-A	GRO-A	GRO-A	and	GRO-A	]	

## Recombinant and Combination Therapies

Agreement being awaited from the Scottish Office re-budget for Consortium for the coming year to purchase Recombinant Factor V111 and 1X. By the end of the year it is hoped that everyone in Scotland, who want it, will be on Recombinant products. Lack of supply of Factor 1X all Factor deficient are on Recombinant 1X. There are still concerns about students who attend English Universities continuing to receive Recombinant Factor, this matter will be discussed at the Center Directors Meeting, when we get a reply to the request to meet with them.

There is a concern about lack of funds in Tayside to provide Combination Therapies for HCV sufferers. This does not appear to be a problem in other areas. A new Combination product called PEG should be available on trial bases soon. It is already licensed in USA. This product is claimed to have fewer side effects and the patient takes less quantities of it in the week. This treatment has been brought to the attention of the Health Committee at the Haemophilia Society.

#### Hepatitis Update

74 MSP's have signed the early day motion laid down by Brian Adam. Members are unhappy at lack of communication and information coming from the office in London. There is still concern over lack of support from medics. Center Directors have been asked to give information to the enquiry and, according to some Doctors, they are not allowed to discuss it with anyone. Another question to be asked at the meeting with the Directors, Where do Center Directors stand on this subject?

## Scottish Officer

An application has been made by the National Office to the Scottish Office for funding for a Scottish Officer for the Society. GRO-A also has been given an application form to look over and fill in with Chief Executive for Lottery Grant funding. The small grants application spoken about at the last meeting has not been applied for. Each group could still complete an application form and try for £500 to £5,000. The members at the meeting asked Phil if it would be possible to see the application to the Lottery before it is sent away.

#### Adventure Weekend

This weekend has been set up for the first weekend in September 1<sup>st</sup> - 4<sup>th</sup>, this is for boys and girls between the ages of 8-16yrs. A week in July 2001 will also be available

Head Office: Chesterfield House 385 Euston Road London NW1 3AU Helpline: 0800 018 6068 Admin: 020 7380 0600 Fax: 020 7387 8220 Email: info@haemophilia.org.uk WebSite: www.haemophilia.org.uk

Patron: HRH The Duchess of Kent President: Lord Morris of Manchester

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at PGL Dunkeld. While we would like to support the children and parents who wish to attend, we would like to point out that the timing could have been better as the Scottish Schools will have only returned two weeks previous after six weeks summer holidays.

# Scottish Group Plans

it was decided by all present that we should formalise this group. We would like to be known as the Scottish Groups Forum. Phil will speak to Karin and ask at the next Trustee meeting to formally ask the Trustees to accept this Group. We agree to meet at least 4 time a year and would like to have some input to appointment of a Scottish Worker if funding is available. Group officers were proposed and seconded, they are, Chairman:- Philip Dolan Proposed GRO-A Seconded GRO-A Vice-Chair:- GRO-A Proposed GRO-A Seconded GRO-A

Vice-Chair:- GRO-A Proposed GRO-A Seconded GRO-A Secretary:- GRO-A Proposed GRO-A Seconded P GRO-A If and when funds are available to our group Barclay Bisset will take on the role of Treasurer.

# **AOCB**

We discussed what groups and hospitals will be participating in the children's party celebrations. South East of Scotland Group were keen to participate. West of Scotland hospital seemed unwilling to take part in this celebration.

Phil had received the Scottish Needs Assessment Programme Consultation Document, which is an overview of Hep C, because of the short time to reply to this document Phil was going to ask for an extension.

Members voiced their disappointment at accessibility of venue for the AGM. People with disabilities don't seem to have been considered. Concern was also voiced due to the timing of the AGM, it appeared to have been brought forward to earlier in the year than in previous years, also some members questioned the co-opting for a second year the co-opted trustees.

Members also asked the question, Why has the blood bank document not been released to the media? Why has this document not been discussed at a Trustee meeting and why are there not more members aware of this document? Certain members are prepared to use this document themselves if the society are not prepared to use it.

Next meeting 3<sup>rd</sup> June at 12.30pm Carolyn will arrange venue in Edinburgh

# **Scottish Groups Forum**

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# 28th March 2003

Minutes of Scottish Groups Forum meeting held on 8<sup>th</sup> March 03 in St Mungo's Museum. Present were members and representatives from most of the Scottish Groups also in attendance was Mr Frank McGuire the lawyer who sat on the Expert Committee who is expert in Medical Negligence Claims Cases.

A presentation was made to GRO-A who has retired as the Chairman of the Perth Group. Philip thanked GRO-A for all his hard work with the Society especially his dedication to the Hep C campaign. GRO-A retirement means the end of the Perth Group.

Frank started his presentation by explaining that there were discrepancies in the newspaper reports about Malcolm Chisholm giving compensation to people with Haemophilia who had Hep C. What the Minister said was he was thinking about giving compensation, the figures mentioned were possibly £20,000 to people with Hep C and were ill and unable to work and also if you had Hep C but had cleared the virus. If you went on to develop cirrhosis of the liver and needed a transplant you would be given another £25,000. This did not give anything to relatives of a person who has died from Hep C. The Minister has also indicated that it would be necessary to have a liver biopsy to determine if you were in the category of having chronic Hep C. This is not necessary to determine if this is the case. A law firm in Glasgow have gifted us a free phone number for people to call and register their claim. It is more appropriate for one lawyer to deal with hundreds of claims than hundreds of lawyers dealing with one client each. Phone No 0800 027 7472.

Frank spoke of the legal position for people who are seeking compensation. People are entitled to compensation if the medical profession did not exercise reasonable care while prescribing treatment. There is a case to answer, where the medical profession knew that there was a virus in the factor (nonA-nonB) as it was called, until heat treatment temperatures were changed to the same in England and virus was called Hep C. There is a question mark over date for this happening 1986-88. People who know when they were infected and if it was after this date they are able to get help through the Consumer Protection Act 1988. this route is closed to most of our members also there is a time limit on taking legal action through the Consumer Protection Act as it must be within 10 years of being infected.

Frank spoke of the moral obligation on the NHS to address the damage and that there is clear discrimination for getting compensation with the infected before or after 1988. The Expert committee set up, comprised of lawyers, medical experts and consumers and the

figures they suggested to Malcolm Chisholm were reached after deliberating on what people could get in court if ever a case could be heard.

Category 1 – Hep C, when informed you are infected, worry, trauma, possibly cleared £10,000 this is probably more than you would get in court.

Category 2 – Chronic Hep C £40,000 + £10,000 speedy payout administratively good, broad figure, executive would not accept open ended amount.

Category 3 – Cirrhosis, transplant Open ended. Smaller category, full compensation as expected in court and if the person dies rights would pass to executor who could still claim. The Expert Committee tried to make their figures palatable to the Executive. They also stated that you could move between the categories which mean no one would be cut off from receiving compensation. The Expert committee don't know the rational behind the figures Malcolm Chisholm came up with. In his figures Category 1 and 2 would get £20,000, this would be an insult to Cat 2 people and Cat 1 people could get nothing. Cat 3 people to get additional £25,000 they are even worse off than Cat 2 as only people living will get money as it doesn't pass on to relatives.

Westminster is holding this up according to Malcolm Chisholm. Scottish Parliaments powers are devolved; certain issues are reserved to Westminster and they claim this is one of these issues. Westminster also claim Scotland cannot give payment from local funds for social security benefits. Expert committee say this is not a benefit it is straight forward compensation and is not a reserved matter. Malcolm Chisholm should take this case to the Lord Advocate as he can say if the is a devolved issue and not a reserved matter. Westminster is using this point of law as they see what repercussions this would have in England and Wales.

Frank suggests that we as a Society write direct to the Lord Advocate and to Malcolm Chisholm stating that this situation cannot be allowed to continue. The Petitions committee could be approached; also MSP's to see what more we can do in Parliament. The Health committee who have been very supportive of our case could possibly put something in front of Parliament. Andy informed us that he has already written to the Petitions committee and has a meeting with them on the 18<sup>th</sup> March

Frank also spoke about the unhelpfulness of Health Boards when they have been approached by patients for their medical records. He informed us that there are procedures that can be taken for obtaining these records and usually a letter from a solicitor is enough for them to produce the necessary records. We should also be asking Malcolm Chisholm to help by waiving the expenses or paying for the expenses incurred for obtaining your own records.