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ANNUAL MEETING
Scotland Haemophilia Directors Group, Scottish Haemophilia Nurses and Scottish Haemophilia Patient Societies

Minutes of meeting held on 28th September 2004 Board Room Glasgow Royal Infirmary

Present:
Prof C A Ludlam (Chair)

Haemophilia Society UK
Mr Graham Whitehead

West of Scotland
Prof G D O Lowe
Prof I D Walker
Dr R C Tait
GRO-A
Mrs A Gibson
GRO-A
GRO-A
GRO-A

East of Scotland
Prof C A Ludlam

Tayside
Dr R Kerr
GRO-A

Highland & Grampian Region
Dr W Murray
GRO-A
GRO-A
GRO-A

Apologies: GRO-A **Susan Hook,** GRO-A **Dr A Thomas, Dr H Watson, Dr E Chalmers, Dr L Horn,** GRO-A , GRO-A **and** GRO-A

Professor Ludlam opened the meeting by welcoming Mr Graham Whitehead, newly appointed Chief Executive of the Haemophilia Society, to the meeting.

1. Minutes of the meeting of 3rd November 2003 were accepted with a minor alteration to the effect that the Haemophilia Society Worker (Ms Helen Lawrie) was not in fact present during the meeting.

2. **Matters Arising**

GRO-A asked for feedback on the post meeting discussions of Haemophilia Directors on whether they should write to the Department of Health on the issue of Hepatitis C. CAL indicated that shortly after the meeting it became clear that the Skipton Fund arrangements were progressing and therefore no action was taken.

3. **vCJD Update**

CAL reviewed the circumstances of the previous notification exercise concerning treatments between 1987 and 1989, and also the more recent notification. In particular, feedback from the previous notification exercise from patients had led Haemophilia Directors to favour the policy of writing to all registered patients in

the recent notification exercise. The patients were asked for their views. There was some concern regarding the apparent delay in notification of patients. However CAL indicated that in both instances, the timing of the notification related to decisions by the Department of Health and delays in advice being forthcoming from the vCJD Incidents Panel. GW intimated that the Haemophilia Society had been invited by the Department of Health to advise on the notification strategy and their input had been successful in at least 3 fronts:

1. Avoiding notification during the summer holiday period.
2. Patients being informed before the media.
3. Haemophilia Centres being given a modest amount of notice about the notification strategy.

Patient representatives raised a variety of concerns and Haemophilia Directors provided some clarification, including:

- Each Haemophilia Centre will write to the patients currently registered at that Centre. If Centres have treated patients between 1980 – 2001, but these patients are no longer registered at that Centre, then the Centre will forward information on those treatments to the Centre where the patient is now registered.
- Since all patients who have received any UK sourced pooled plasma product between 1980 and 2001 will be treated similarly with regard to Public Health precautions, there would appear to be no legal concern if some patients do not wish to know whether they have received any implicated batches.
- There did appear to be mixed messages within the notification strategy regarding dental treatment, since patients were asked to notify their dentist however neither Haemophilia Centres nor the Health Protection Agency were writing to dentists. GW was able to inform the group that he had recently received communication from the Dental Council indicating that they will not be taking any additional measures for 'at risk' haemophilia patients and therefore their dental care will be unaffected. It therefore seemed that the reason for informing dentists was just in case the dentist would subsequently refer a patient to a hospital surgeon for a high-risk procedure (e.g. tonsillectomy).
- It was not thought that a haemophilia patient acting as a first aider would be at risk of onward transmission of vCJD, or indeed other blood borne pathogens, unless there was a significant risk of injury to the haemophilia patient.

GRO-A raised the issue of insurance reports for haemophilia patients and whether their 'at risk' category for vCJD public health reasons would be revealed to insurance companies. CAL indicated that he was not aware that such a situation had arisen to date however it was obviously uncertain as to what questions insurance companies may ask in the future. GRO-A indicated that he had seen some draft insurance forms which requested information as to whether the applicant was a haemophilia patient or the partner of a haemophilia patient. This naturally caused some concern amongst haemophilia patients.

4. Hepatitis C

Treatment issues

GRO-A asked if there was a recommended frequency of ultrasound scan testing and whether there were any trigger levels of alphaphetaprotein (AFP) which might precipitate a particular management strategy. Regarding the frequency of ultrasound scanning of the liver there appeared to be great variation between Centres (once per year up to 3 times per year). CAL indicated that ultrasound

scanning was not particularly precise and may not pick up all liver cancers. However UK Guidelines did suggest a target of 6 monthly ultrasound examination for patients thought to have cirrhosis. It was of course difficult to be certain whether a patient had cirrhosis without a liver biopsy. Regarding AFP levels, CAL indicated that a rising pattern of AFP results was perhaps more important than a specific level.

GL intimated that the Scottish and Northern Ireland Haemophilia Directors were in the process of undertaking an audit of HCV treatment and outcome and in addition the SIGN Guideline Group were preparing a guideline on HCV management.

Skipton Fund

The patients asked how much input Haemophilia Directors had had in design of the Skipton Fund form. The Directors indicated that they had no input and indeed Directors saw the form for the first time when patients started to submit these for completion. No Haemophilia Directors have seen Form 2, although PD had been given sight of this draft form for comment. His initial thought was that it was not particularly patient friendly.

GW indicated that he had recently written to the McFarlane Trust regarding his concern about increasing delays in processing Skipton Fund Request Forms. The current delay is in the region of 12 weeks. It is hoped that more staff may be appointed to assist the McFarlane Trust during this busy period. The meeting also raised concerns about the lack of a medical advisor to the Skipton Fund and the lack of input from Haemophilia Directors to drafting of the Skipton Forms 1 and 2.

5. Coagulation Factor Treatments

Use of 3rd Generation Advate

CAL indicated that this was now replacing Recombinate in all Centres throughout Scotland. As usual individual patients are at liberty to discuss their specific treatment with their Haemophilia Centre.

Home Delivery of Treatment

It was noted that this would be particularly valuable for those living in geographically isolated areas. WM indicated that some patients in North Scotland already benefited from local delivery arrangements. Regarding a Scottish wide home delivery service, discussions are ongoing with Scottish Healthcare Supplies and National Services Division who are responsible for contractual and financing issues. Unfortunately there is as yet no timescale for implementation of a home delivery service.

It was noted that some patients may not wish home delivery and Haemophilia Directors agreed that this was quite acceptable.

Treatment Records

Concern was raised over the charge of £15 being made to patients who wish a copy of their National Haemophilia Database records. CAL was uncertain as to whether this was a statutory charge but agreed to enquire of NHD the rules as to who has to pay this charge and why. GRO-A pointed out that the output from the database does not actually state where the data has come from (i.e. the National Haemophilia Database) and this could also be addressed.

CAL

Although Malcolm Chisholm had indicated that haemophilia patients should gain access to their medical records free of charge, it did appear that the odd patient was being charged. CAL suggested that this should be taken up with the local Haemophilia Director or perhaps should be an issue for the Haemophilia Society to address.

Women with bleeding disorders

GRO-A enquired as to what guidelines were in place for management of such patients. CAL indicated that there were a variety of guidelines for specific conditions (e.g. von Willebrand's Disease and

Rare Bleeding disorders) as well as specific guidelines on pregnancy. It was also noted that Aberdeen Royal Infirmary undertook Carrier Clinics and CT reported that these were also in place in the West of Scotland. GW indicated that this would also be a focus for the Haemophilia Society who will be promoting management and treatment of von Willebrand's Disease as well as an equal balance of research activities relating to psycho-social issues of male and female bleeding disorders. CAL reported that following the recent publication of the Genetics Guideline there would be a drive towards improved counselling of haemophilia families.

Advoy

GRO-A enquired as to the status of this system provided by Baxter. It was reported that many Centres had offered this or alternative recording devices to appropriate patients.

6. Haemophilia Society in Scotland

GRO-A clarified for the group that the Haemophilia Forum had been set up in Scotland by the Haemophilia Society in Scotland. This was effectively an umbrella organisation for all the separate regional groups which remained independent. Essentially the Haemophilia Forum was part of the Haemophilia Society. It was however acknowledged that the Forum tended to address more political issues while the Society Groups were more involved in fundraising. GW indicated that the Forum was an important group, being able to raise countrywide (Scotland) issues to the Haemophilia Society.

GRO-A reported on the recent formation of the new Highland Group which had had a successful first meeting several weeks previously. That meeting had identified concerns over the level of treatment available at the local Centre. Some patients had decided to seek treatment at Aberdeen Royal Infirmary and 1 patient had attended a Centre outwith Scotland. Discussion followed at the end of which the various routes by which patients could raise concerns about their treatment were raised. CAL and CT reminded the group of the discussion at the end of the meeting in 2003 (under Item 10 AOCB) which outlined the route by which individual patients or their representative could discuss issues with the lead consultant at the appropriate Comprehensive Care Centre or with the hospital directly.

Scottish Project and Patient Questionnaire Survey (needs assessment)

GW commented that the Scottish Project supported by the community fund had suffered many difficulties because of the stop/start problem. Funding had now ceased and he would be discussing with the Scottish Groups what future projects might be undertaken in Scotland. GW was surprised to hear that Haemophilia Directors in Scotland had not yet received a report from the Needs Assessment exercise and he promised that this would be forwarded to them within a few weeks. CAL indicated that Haemophilia Directors and Centres would be pleased to collaborate on future ventures. GW

7. AOCB

Transfer of children to Adult Centres

GRO-A asked if there was a written policy as to this process. CT reported that there was no written policy but he did outline the procedure in the West of Scotland. It was suggested that if there were specific issues then they should be addressed to the appropriate Haemophilia Directors.

Out of Hours Services

GRO-A queried local policies. CAL indicated that local policies obviously reflected the location and services available out of hours at individual sites. However all haemophilia patients should be made aware of the contact numbers for direct access to haemophilia care at their own Centre.

Audit

GRO-A enquired as to how patients might receive feedback from their participation in local audit (e.g. completion of anonymous questionnaire when the Comprehensive Care Centres are visited). GL reported that UKHCDO would be producing a final report on the 2003 audit exercise and this may be available at the forthcoming AGM. It was also noted that with increased public access to documents and reports, patients may be able to access these in the future.

Requests for assistance with Haemophilia Documentary

GRO-A indicated that he was making a film on haemophilia issues and requested assistance and commentary from some haemophilia doctors. The chairman indicated that it would be best if he approached individual Directors directly. GRO-A also requested financial support for the patients' fight for judicial review of Hepatitis C issues. Again the Chairman suggested that individual Directors were contacted directly.

8. Format of Future Meetings in Scotland

CAL asked the group whether the current format should be changed in any way and whether additional meetings were required. GW indicated that this present meeting was very helpful and should be continued. GRO-A suggested that it may be useful to have an Alliance type meeting to include a wider group of participants. It was however noted that this had been suggested for 2003 but it had proved impossible to arrange such a meeting. It was also important that such a meeting had a clear purpose and was set at a time to suit the majority of participating individuals. GRO-A asked if the current Group had a terms of reference for the existing meeting. CAL reported that he was not aware of any, however he would be happy to look at any proposals from the Haemophilia Patients Groups and Haemophilia Directors would consider this.

9. Date of Next Meeting

It was agreed to set a date for the 2005 annual meeting with haemophilia patients and nurses. This was provisionally set at Monday 12th September 2004. The meeting will be held in Edinburgh (exact venue and start time to be arranged).