

Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392157

NEEDS ASSESSMENT *PROGRESS REPORT*

- 1 As part of the Strategic Plan it was agreed that a needs assessment exercise would be carried out to identify the varying needs of people with haemophilia and their families. From this assessment, proposals for modified and new services would be developed with the intention of implementing them in 1994.
- 2 Over the last few months questionnaires were sent out to 10 different categories of members covering 477 people (see appendix). In addition all members were informed of the questionnaire through Update and encouraged to ask for a copy. Copies were also made available at the AGM. The overall response rate was disappointing (about 25% but this varied between categories) given that we were asking people what they wanted and a free post envelope was provided. A reminder was sent to the first two categories and this produced a slight increase but it was decided that it was not worth repeating this for the other categories.
- 3 The next stage is to analyse the replies. As part of this exercise we are using a volunteer to ring up those people who said on their questionnaire that they would be happy to discuss the questions further. This will be particularly useful for getting feedback on ideas for new services. It is hoped that a full report will be completed during September. Outlined below are some general impressions from an initial reading of the replies.
- 4 Most people are happy with what the Society does – there were very few complaints. Many people made little or no use of the Society's services but were happy to know that we were there if they needed something. Not everyone was familiar with all the services that the Society offered or the publications that we provide. Different people had different needs even if they fell into the same category. For example most people wanted contact with others and saw this as very important but for others the last thing they wanted was to talk to other people with haemophilia. The Bulletin was highly praised but many people wanted the medical articles to be in simpler terms. Update was seen to be less relevant by some. The best thought of service was clearly the provision of Armourpagers. Adventure holidays were also praised.
- 5 A number of ideas for new or modified services are being considered and the follow up telephone interviews are focusing on these. There is a clear need for material and support aimed directly at parents of newly diagnosed children. An introductory pack or file for new members with young children would be popular. Fact sheets on specific aspects of haemophilia care or aimed at particular groups might also be considered. There appears to be support for Haemophilia days but some people emphasised that these should be local as they were not prepared to travel far.

- 6 The idea of a helpline or at least a "member services" line has received support. This would enable people to contact direct someone who could help them or at least make an appropriate referral. Some questioned whether such a line would be viable given the relatively small number of people with haemophilia. It might be appropriate to begin by offering this service during specific working hours and then explore the possibility of using volunteers outside office hours.
- 7 Contact with others for mutual support was given a high priority by many but a some felt that they had not got this from the Society. We need to look at models other than the existing local Groups. One possibility would be finding ways of supporting small numbers of individuals who want to help each other but do not want the burdens and extra work involved in being part of formal local Group. It may be that some Centres help facilitate this but we should try and increase our contact with any such group and seek to provide them with information and other support they may need.
- 8 Many people, particularly parents, wanted contact with one or two other people who were in the same position or had already experienced a particular problem. A number expressed the view that they did not get this contact/support, in some cases even where a local Group existed. With the new computing system and the establishment of a better database it might be possible to encourage members to ring the Society if they want to be put in touch with other people with similar experiences or concerns. A register of people prepared to talk, correspond or meet with others could be established. This idea has received support from those who were phoned for a follow up interview and almost all said they would be willing to be on a register of this kind.
- 9 These ideas and others will be looked at in detail when the questionnaires are analyzed and when respondents are telephoned for follow up interviews. Any modifications to existing services and proposals for new services will be developed and costed for consideration by the Committee, with the intention of implementation in 1994 if funding is available.

SUMMARY OF QUESTIONNAIRES

		colour sent	date sent	return by	no's sent out		returned	reminders
1	The parent of young child with haemophilia (50)	grey	15/3/93	29/3/93	50		18	15/4/93 (41)
2	A parent of a school aged child with haemophilia (50)	pink	30/4/93	17/4/93	55		13	/
3	A parent of a teenager with haemophilia (50)	light/green	25/3/93	14/4/93	52		17	15/4/93 (46)
4	Adults with mobility allowance (30)	lemon	4/6/93	21/6/93	28		4	/
5	Health Care Professionals (43) MAP's (8)	gold	27/5/93	14/6/93	43	8	18	/
6	An adult with haemophilia (98 : so will include HIV+s and those with mobility problems)	gold	7/6/93	21/6/93	95		12	/
7	Someone who attends a small Centre rather than one of the bigger Centres (25 : Hull, Colchester, Brighton, Eastbourne, Tunbridge Wells, Bournemouth)	light/blue	27/5/93	14/6/93	24		5	/
8	Someone who is prepared to travel a long distance to attend a good Centre (50 : from St Thomas' and Royal Free)	peach	27/5/93	14/6/93	48		9	/
9	Someone who lives in an area where the Society has no local Group (29 : Bristol, Bradford, Eastbourne, Bournemouth, St Georges, Hammersmith)	orange	4/6/93	21/6/93	29		5	/
10	Someone who has asked not to be put in contact with a local Group (50)	dark/blue	28/5/93	14/6/93	45		10	/
TOTALS					total sent = 477		total rtd = 120	