

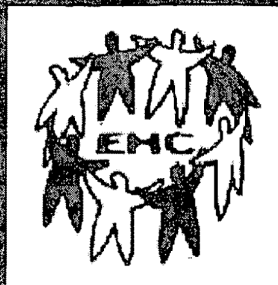
Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392197



**EUROPEAN
HAEMOPHILIA
CONSORTIUM**

**ANNUAL REPORT
2002**

Steering Committee Members

Chairman	Gordon Clarke	(United Kingdom)	gordonclarke@	GRO-C
Committee	Jean Pierre Lehoux	(France)	info@afh.asso.fr	(no attachments)
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"	Yuri Zhulyov	(Russia)	aph@	GRO-C
"	Brian O'Mahony	(WFH ex officio)	brian@	GRO-C
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Gordon and members of the Armenian delegation
at an EHC Meeting in Seville 2002

Chairman's Overview



This year the EHC has continued to develop and extend its membership and scope of activities in a fast changing and challenging environment. With our membership of 43 national member organisations (NMOs) now at its highest since the EHC was founded in 1987, there are increasing needs for support, for sharing information and advice between members.

Our continuing goal is to support and empower EHC member organisations so that they can be strong advocates for people with haemophilia in their own countries and thus achieve the best possible treatment and care.

At the same time our external environment is changing. The enlargement of the European Union has important implications for many of our EHC members who are in countries now waiting to join. Enlargement impacts directly on haemophilia care, as the regulatory frameworks of the EU, notably the European Medicines Evaluation Agency (EMA) are extending to cover new EU members. This has implications for blood product safety and supply, a topic, which was high profile in 2002, when the European Blood Directive was under review.

That enlargement process in itself highlights the differing standards of haemophilia care in this region, an imbalance that the EHC has long campaigned to change. Whilst people with haemophilia in the more developed and affluent EU countries can expect the best modern treatment, many of those in the new joining countries are receiving only basic care. This makes it vital for the EHC to engage in the enlargement process and to represent the interests of people with haemophilia in the changing Europe.

The EHC has also been keen to network at European level with other health and disability groups that may share common interests. Our membership of the European Disability Forum has continued to be valuable in this respect. We are also in the process of joining Eurordis, another disability forum, which will enhance further our informational base.

I must also thank my fellow members of the EHC steering committee and the staff team at the secretariat for their hard work. We set out an ambitious action plan for 2002. The rest of this report outlines the progress made in the various programmes of work to meet our goals. Finally, our allies in all their respective livery are important partners, not only because of the funding support from some for which we are grateful but also for the sharing of information and communications that are part of our relationship.

For the future it remains my personal ambition that as EHC grows in size, stature and self determination capability, our voice will not only be sought in many forums but equally, our participation will advance from token to integral. This surely is the true test of equal partnership.

Gordon Clarke
Chairman
March 2003

Blood Safety and Supply

Goals for the year

- To lobby for improvement in the proposed EU Blood Directive
- To contribute to WFH Global Forum on safety and supply
- To develop plans to aid provision of concentrate to non-EU States
- To participate in the debate on management of products in short supply
- To liaise with all relevant parties including regulators, industry and clinical and scientific parties

This last year saw a very active debate on blood safety and supply in the context of the EU Blood Directive, which was reviewed and revised by the European Parliament. This led to strong exchanges of views on the particular question of remuneration for blood/plasma donors.

Throughout this debate the EHC worked to ensure that concerns about supply were not forgotten when considering the proposal to stop the use of plasma from remunerated donors. The eventual outcome of this process was satisfactory, as the potential risk of a reduced supply of plasma products has been avoided. The revised Blood Directive does not involve an outright ban on use of plasma, whilst respecting the principle of encouraging voluntary blood donor systems.

Following the recombinant shortages, which dominated 2001, and continuing concerns about the possibility that variant CJD might be transmitted in blood, the WFH Global Conference on Safety and Supply in January 2002 was very timely. This meeting brought together industry, regulatory bodies and patient groups. The EHC chairman Gordon Clarke was one of the speakers, giving a patients perspective on vCJD.

The EHC was also invited to take part in the expert workshop on TSEs and vCJD held by the European Medicines Evaluation Agency in June. The meeting involved leading scientific experts from around the world. Karin Pappenheim, representing the EHC, made a presentation on the patient's perspective; a full report of the meeting written by Dr Paul Giangrande was then published in the EHC newsletter so that the information could be shared with members.

General Haemophilia Care

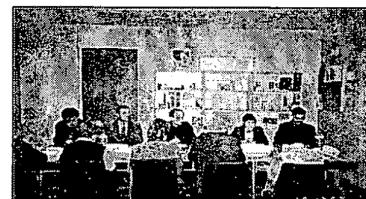
Goals for the year

- To represent the needs of people with haemophilia and related bleeding disorders
- To monitor developments in gene therapy
- To generate discussion on the establishment of a European database on people with haemophilia (PwH)
- To establish a clinical and scientific EHC advisory group
- To lobby for improvement in patients' platforms within the EU

The EHC's major challenge is to raise the standards of treatment and care for haemophilia patients in countries where little or no treatment is yet available. Working with the World Federation, the EHC chairman Gordon Clarke made visits to Bosnia, Azerbaijan, and Armenia during the year and met with Government officials, clinicians and patient groups regarding the enhancement of treatment facilities.

Our 15th annual members meeting which took place in Riga, Latvia also provided support for the NMO in that country. By generating press and media publicity around the conference, and by inviting a Latvian health ministry representative to take part in the event, the EHC was able to put forward a strong message about the treatment needs of people with haemophilia.

The EHC steering committee member Yuri Zhulyov visited the regular conference of the Ukrainian Hemophilia Union in Kiev city. At the conference the election of a new president and board took place and new directions for the UHU were discussed.



Meeting of the Ukrainian Hemophilia Union in Kiev

On September 4 – 6, the Russian Hemophilia Society (RHS) held its first chapter training workshop. Over 135 members from 45 regional chapters and 6 countries of the former Soviet Union received training in media relations, chapter management, finances, and working with families.

The EHC was active in Romania during the year, when our national member organisation raised concerns about the costs and supply of haemophilia treatment. EHC chairman Gordon Clarke wrote to the Romanian government to apply pressure for increased supplies of treatment products.

Support for and Communication with Members

Goals for the year

- To modify and formalise procedures for Annual meetings
- To investigate all opportunities to introduce improved translation facilities
- To expand circulation of the newsletter
- To review and revise the provision of the EHC summer camp
- To enhance level of information obtained from surveys
- To facilitate development of individual NMO annual plans
- To assist NMOs with implementation of annual plans where appropriate

One of the EHC's most important roles is exchange of information between members. This took place not only through our member meetings during the year but through the website, which was significantly improved and the two issues of the newsletter produced in 2002. In response to requests the secretariat produced briefings for members on specific topics, such as the status of campaigns for compensation for the hepatitis virus.



EHC meeting in Riga

In 2002 there were two member's meetings, the first in Seville in May and the second, our 15th annual conference in Riga, Latvia. Over 85 delegates from 35 countries attended the conference, which was organised jointly by the EHC secretariat, the World Federation and the Latvian Society. In response to requests from members, there was a large element of training at the 2002 conference with workshops and presentations on fundraising and project planning skills.

With a large proportion of EHC member organisations now in Baltic and newly independent states (NIS), we have worked hard to improve communication by means of Russian translation. Thanks to Russian interpreters, these NMOs were able to participate more fully in the conference in Riga. Our newsletter and other information is also regularly translated into Russian by the Russian Haemophilia Society making it more accessible to members in those NIS countries and Baltic states.

The EHC continues to use ad hoc member surveys as a means of gathering information, for instance, on members' views on the possible risks of variant CJD. During the year the steering committee also made plans for a further members survey in 2003, which will gather information on the situation and the key issues in each member country.

Finally, the steering committee reviewed the role of the EHC summer camp that has been running for many years by international groups of volunteers with support from various pharmaceutical companies. This involved a lively debate with members. As a result, it was decided that the summer camp should be continued because it meets a very particular need amongst the 18-30 year old age group for whom there is little other provision, and at the same time serves to bring together young people with haemophilia from very different parts of Europe. Plans are now in progress for the next summer camp to be held in France in June 2003.

External Relations

Goals for the year

- To maintain existing and create new opportunities to exchange information
- To investigate opportunities to build EHC's profile within Europe
- To share EHC's development experience with other interested regions of the world
- To contribute to the working of the European Disability Forum
- To provide monitoring and advice for WFH on European policy matters

Maintaining productive relationships with European institutions, regulatory bodies, industry and voluntary groups is a continuing priority for the EHC as a means of influencing policy for the good of people with haemophilia. This includes a continuing dialogue with industry through the Plasma Proteins Therapeutics Association (PPTA) Europe and the European Plasma Fractionation Association (EPFA), both of which meet regularly with the EHC steering committee. The Chairman, Gordon Clarke, has also opened a line of communication with the European Blood Alliance and plans to give a formal address to the Alliance at their meeting in Spring 2003.

The chairman and steering committee member Daniel Lighezan participated in the EPFA/PPTA conference in Rome in May about new routes to clinical excellence and global priorities.

As a member of the European Disability Forum, the EHC is kept very much in touch with relevant developments at the European Commission and Parliament, and has an opportunity to have a say in debates affecting people with long-term medical conditions and disabilities.

The EHC took the chance to have a stand at the World Federation Congress in Seville in May so helping to raise our profile internationally.

Organisational Development

Goals for the year

- To review and revise the structure of the Steering Committee
- To amend Steering Committee roles and responsibilities to better reflect key objectives
- To amend the procedure for election of Steering Committee members

The current EHC steering committee members come from the UK, France, Sweden, Switzerland and Russia and Romania, so bringing together the perspective of developing eastern and newly independent countries with those that already have good quality haemophilia care. Under our constitution, elections are held every two years. Gordon Clarke will be retiring as chairman, and some other members will also stand down. Hence in 2003 our member organisations will be voting for a new chair and steering committee.

The committee continued to work hard to improve its own effectiveness in 2002 by assigning each member a particular area of responsibility. By holding more frequent meetings quarterly by teleconference it was possible to progress delegated work more efficiently and keep in touch across the very large geographic region.

The committee also reviewed the constitution of the EHC in consultation with members in 2002, including the election process. With the huge growth in the organisation since its foundation 15 years ago, there is a need to revise and update the constitution. This work will be carried forward in 2003.

A new understanding was reached with the World Federation of Hemophilia (WFH) about the relationship between WFH and EHC. One driver for this was the desire of many EHC members for an independent organisation. In 2003 this will be followed through with a feasibility study to be conducted into the possible means of funding the EHC as an independent entity with its own separate office in Europe. Currently the financial support received from WFH remains an important source of funding for EHC, and it is not yet certain that this can be replaced by alternative funding sources in Europe.

At the same time, the WFH's requirements have changed with regard to its relationship with EHC. Until now the EHC secretariat has acted and has been referred to as a regional office of WFH. In future this will no longer be the case, although clearly strong lines of communication will be maintained in the future.

Another key issue discussed in 2002 was the location of the secretariat, which has been managed by the UK Society in London since 1999. It is hoped that another member organisation will be able to take on this role in 2003.

Fundraising

Goals for the year

- To research and apply for appropriate grants within the EU
- To centralise sponsorship approaches to pharmaceutical companies
- To review level and procedure for calculating NMO membership fees
- To develop project sponsorship plans for new areas of Consortium work.

Much effort during the year went into developing the EHC's relationships with the pharmaceutical companies that provide funding for the members conference, summer camp and for the running costs.

A priority was to learn more about the different funding sources available from Europe, which led to an application to TACIS programme (unfortunately unsuccessful). The steering committee has recently commissioned a review by an expert consultant of the options for securing greater funding from pan-European and international bodies.

Reviewing the issue of EHC membership fees, the steering committee were very aware that the growth in membership from countries with very limited resources means that many NMOs cannot contribute more. This poses a difficulty for future funding of the EHC, as it does not seem likely that income from membership fees can be much increased above current levels.

Financial Statement

The continuing effort to increase the EHC's income is still proving a challenge. Although it is pleasing to report that we have managed to raise enough during the year to cover our core activities, this does not permit any growth or expansion for the organisation. Both income and expenditure in 2002 have been at a similar level to the previous year, and we have again been able to bring forward a small surplus to 2003.

We are grateful to the companies that have supported the EHC work in 2002 either in the form of core funding or by sponsoring our members' conference:

- **Biotest Pharma GMBH**
- **Baxter Hyland Immuno**
- **Bayer**
- **Shanghai RAAS**
- **Alpha Therapeutic**
- **Octapharma AB**

The grant contributed by the **Swedish Aid Fund for Solidarity (SHIA)** to support the members' conferences in 2001 and 2002 is also much appreciated.

Year 2002 - EHC Summary of Income and Expenditure up to 31.12.02

	Notes	2002 Sterling	2002 Euro	2001 Sterling	2001 Euro
Income					
Contributions NMOs		4,689.55	7,327.42	4,127.15	6,765.82
Contribution WFH		5,457.51	8,527.36	4,390.49	7,197.52
Total		10,147.06	15,854.78	8,517.64	13,963.34
Contributions industry	1	10,024.07	15,662.61	9,121.78	14,953.74
Conference fee		671.15	1,048.68	0.00	0.00
Total income		20,842.28	32,566.07	17,639.42	28,917.08
Expenditure					
Staff time		7,122.75	11,129.30	7,435.00	12,188.52
Tel + fax	2	2,982.38	4,659.97	386.52	633.64
Postage + bank fees		284.01	443.77	108.30	177.54
Copy/print		35.25	55.08	0.00	0.00
Travel		3,843.23	6,005.05	1,909.76	3,130.75
Steering Committee meet		4,600.57	7,188.39	4,878.57	7,997.66
Subscriptions		0.00	0.00	642.31	1,052.97
Total expenditure		18,868.19	29,481.55	15,360.46	25,181.08
Surplus/(deficit)		1,974.09	3,084.52	2,278.96	3,736.00

Notes:

- 1** Contributions from industry:
10,000 Euros received from Bayer - core funding
5,000 Euros received from Biotest - core funding
- 2** Teleconferencing costs

Balance sheet as at 31 December 2002

	Note	2002 £	2002 Euros
Current assets			
Debtors	1	6,932.71	10,832.36
Prepayments		0.00	0.00
Cash at bank		<u>42,368.95</u>	<u>66,201.48</u>
		49,301.66	77,033.84
Current Liabilities			
Creditors	2	37,244.06	58,193.84
Unpresented cheques		77.00	120.31
2002 Latvia Conference	3	<u>2,684.62</u>	<u>4,194.72</u>
		40,005.68	62,508.87
Net current assets		<u>9,295.98</u>	<u>14,524.97</u>
Funds			
Balance brought forward from 2001		7,733.64	12,083.81
Surplus/deficit for 2002		1,974.09	3,084.52
		<u>9,707.73</u>	<u>15,168.33</u>

Notes:

1Debtors		
SHIA	5,849.80	9,140.32
EHC Conference fee	671.15	1,048.68
UK Membership fee (for 2001 & 2002)	411.75	643.36
	<u>6,932.71</u>	<u>10,832.36</u>
2Creditors		
UK Haemophilia Society:		
Steering committee	3,026.50	4,728.91
Postage	70.82	110.66
Travel	2,370.54	3,703.97
Telephone	597.74	933.97
Staff Time (for 2001 & 2002)	14,557.75	22,746.48
2002 Latvia Conference costs	2,833.54	4,427.41
Additional Staff Time - Latvia conference	2,366.00	3,696.88
	<u>25,822.89</u>	<u>40,348.27</u>
WFH (Latvia Conference costs)	9,920.00	15,500.00
Latvian Society costs	1,501.17	2,345.58
Total Creditors	<u>37,244.06</u>	<u>58,193.84</u>

32002 Latvia Conference Surplus (accounts attached)
 Surplus is divided 25% to EHC, 75% to host country

EHC Conference 2002

Income	Sterling	Euros
Delegates fees	2,719.70	4,249.53
Industry sponsorship	29,987.79	46,855.92
SHIA grant	5,849.80	9,140.32
TOTAL REVENUE	38,557.29	60,245.77
Expenditure		
Meeting coordination WFH	3,200.00	5,000.00
Sponsor management WFH	6,720.00	10,500.00
Hotel	13,306.71	20,791.73
Travel	7,755.94	12,118.66
Staff costs	2,366.00	3,696.88
Latvian Society costs	1,501.17	2,345.57
Translator	401.26	626.97
Bank charges	221.60	346.25
Other	400.00	625.00
TOTAL COSTS	35,872.68	56,051.06
Surplus/deficit	2,684.61	4,194.71