



**THE
HAEMOPHILIA
SOCIETY**

The Haemophilia Society
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THE HAEMOPHILIA SOCIETY CHAIRMAN'S CONFERENCE



19 -20 November 1994
The De Vere Hotel, Coventry
PROGRAMME

Saturday 19 November

9.30 - 11.00 Registration

10.30 Coffee: Three Spires Room

11.00 Conference Welcome: Connaught Room
The Reverend Prebendary Alan Tanner, Chairman of the Society

11.15 - 12.45 Scientific Symposium: Connaught Room
The Potential of Recombinant Factor VIII in Haemophilia
Dr Paul Giangrande, Haemophilia Centre Director, Churchill Hospital, Oxford
Dr Jonathan Cooke, Director of Pharmacy, South Manchester University Hospitals
NHS Trust

12.45 - 2.15 Lunch: Three Spires Room

2.15 - 3.45 Discussion Workshops
Each Workshop will have a 20 - 30 minute presentation followed by questions and discussions
There is a choice of the following 3 workshops:

a) HIV Treatment: Cavendish Suite
Dr Shahmanesh, Consultant Physician in GU Medicine, The General Hospital,
Birmingham

b) The Management of Inhibitors: Connaught Room
Dr Charles Hay, Haemophilia Centre Director, Liverpool

c) The Management of von Willebrand Disease: Pine Suite
Dr Paula Bolton-Maggs, Consultant Paediatric Haematologist, Alder Hey Childrens
Hospital, Liverpool

3.45 - 4.15 Tea/Coffee Three Spires Room

4.15 - 5.30 Drop-in Meetings

a)	Benefits Advice	Three Spires
b)	Birchgrove Group	Pine Suite
c)	Children and Families Worker	Cavendish Suite

CARING FOR PEOPLE WITH HAEMOPHILIA

d)	Fund-raising	Three Spires
e)	Hepatitis Support Group	Connaught Room
f)	Macfarlane Trust	Connaught Room
g)	Support to Parents	Cavendish Suite
7.30	Pre-dinner drinks	Connaught Room
8.00	Evening Meal	Connaught Room

Sunday 20 November

8.00 - 8.30	Communion Service	Cathedral Suite
8.00 - 9.00	Breakfast	Three Spires Room

9.30 - 10.45 Discussion Workshops

Each Workshop will have a 20 -30 ,minute presentation followed by questions and discussions
There is a choice of the following 3 workshops

a) Hepatitis C **Connaught Room**
Dr D Mutimer, Consultant Physician, Queen Elizabeth Hospital Birmingham

b) Haemophilia and Orthopaedics **Pine Suite**
(Speaker to be announced)

c) Prophylactic Treatment **Cavendish Suite**
Kate Khair, Clinical Nurse Specialist, Great Ormond Street Hospital for Sick Children, London
Katherine Spence, Haemophilia Nurse Manager, St Thomas' Hospital, London

10.45 - 11.15	Tea/ Coffee	Three Spires Room
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11.15 - 12.15 Drop-in Meetings

a)	Benefits Advice	Three Spires Room
b)	Birchgrove Group	Pine Suite
c)	Children and Families Worker	Cavendish Suite
d)	Fund-raising	Three Spires Room
e)	Hepatitis Support Group	Connaught Room
f)	Macfarlane Trust	Connaught Room
g)	Parent Support Group	Cavendish Suite

12.15 - 1.15	Key Note Lecture	
	Haemophilia and Gene Therapy	Connaught Room
	Professor Ian Peake, Royal Hallamshire Hospital, Sheffield	

1.15	Closing Session & Annual Draw	Connaught Room
	Reverend Prebendary Alan Tanner, Haemophilia Society Chairman	

1.30 - 2.30	Lunch	
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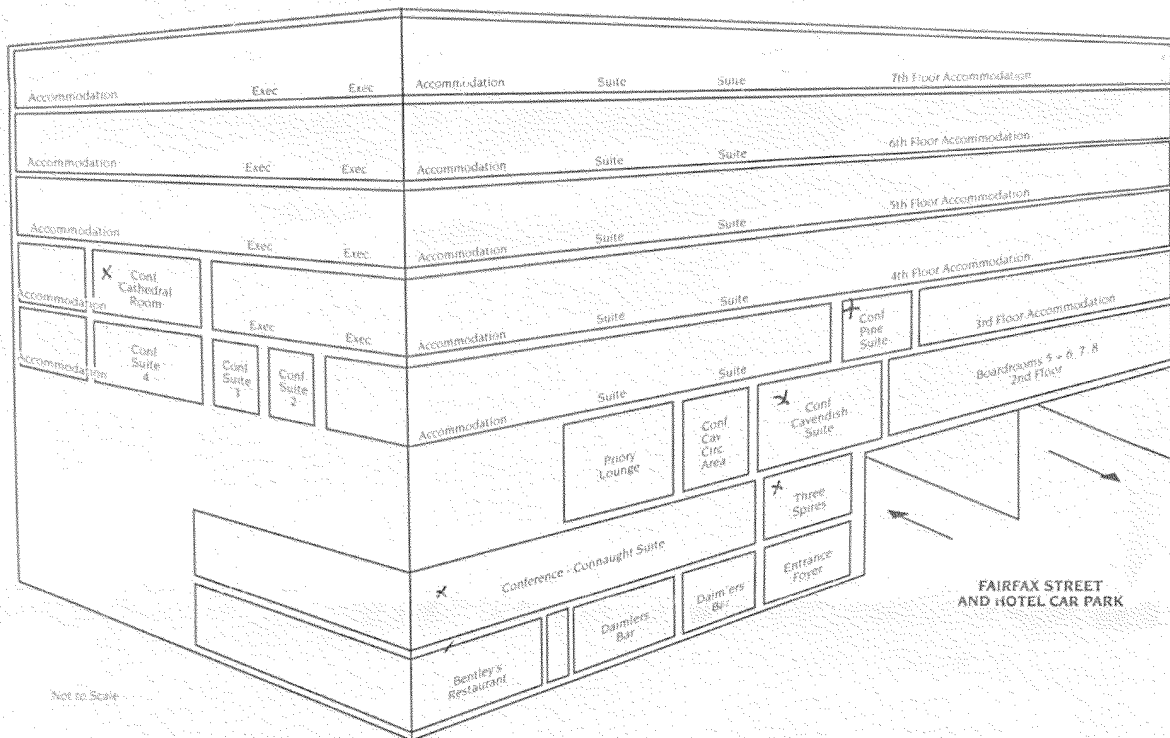
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The Society wishes to thank the following companies for supporting this conference:

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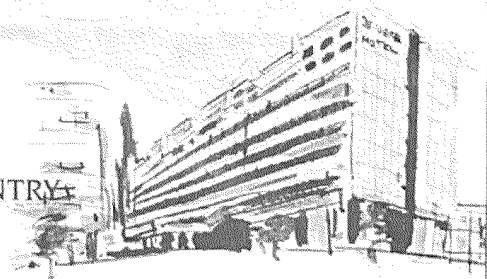
ROOM FACILITIES

LAYOUT OF CONFERENCE SUITES AND ACCOMMODATION



DE VERE HOTEL COVENTRY

DE VERE HOTELS



INFORMATION SHEET

WELCOME to the 1994 Chairman's Conference. This sheet aims to give you some basic information about the arrangements and the hotel.

CHECKING IN AND CHECKING OUT OF THE HOTEL

Due to the large numbers of people attending the conference, the hotel are unable to provide special facilities for checking in and out. Therefore, your room may not be available when you arrive at the hotel. The hotel receptionist will explain the procedure to you, and will arrange for your baggage to be stored until your room is available. This will probably be after 2pm.

On Sunday morning, you must check out of your room before 11.00am. Again, the hotel will be able to store your baggage until you leave.

ROOM LOCATIONS

A detailed programme for the weekend and a cross-section map of the hotel is included with your registration pack. This gives details of the rooms for the conference sessions and for meals. If you are unsure of the location of any room please ask a member of the hotel staff for guidance. All rooms are accessible by lift.

CAR PARKING

To exit from the car park, please obtain a token from reception.

YOUR RESPONSIBILITIES

Whilst we have a majority of the rooms booked in the hotel this weekend, it is still a public building and the general rules apply:

Fire regulations: Please read the fire instructions in your hotel room and locate the exits as advised. In the conference sessions the emergency exits will be clearly marked for each room.

Personal property: Please take care with your belongings at all times. Any valuable items should be left in the hotel's safe. The Haemophilia Society cannot be liable for any loss or damage to personal items whilst attending the conference.

In the event of problems with your hotel accommodation, please contact reception. If you have other problems or queries please locate a member of the Haemophilia Society staff.

DROP-IN MEETINGS

These will be held on **Saturday between 4.15 and 5.30** and again on **Sunday between 11.15 and 12.15**. The meetings will provide an opportunity to meet and talk with Society staff, trustees and members directly involved in some of the Society's activities. In each case there will be a short presentation followed by discussions and questions. These sessions will be informal. Do come along and find out more about what the Society is doing.

a) Benefits Advice

Come along and meet Kate Richards, the Society's Members Services Officer who is responsible for giving information and advice to members on a range of issues including welfare benefits. She will explain how she can help members by advising on how to fill in the application forms, by writing letters of support and in some cases by representing members at tribunals.

b) Birchgrove Group

If you wish to meet members of the Birchgrove Group, the self help group for people with haemophilia and HIV, they will be available to explain who they are and what they are doing to help and support people with haemophilia and HIV.

c) Children and Family Worker

Liz Cox is seconded from Barnardos to the Society to work with children infected or affected by haemophilia and HIV. She will be explaining the Society's new proposal for a children and family worker whose role it will be to ensure that children and families affected by haemophilia and HIV get the services and support they need both from the Society and statutory authorities.

d) Fund-raising

Come along and meet John Berry who is responsible for the Society's fund-raising. He will tell you about the forthcoming activities and give you ideas on how you can raise money for the Society. He is also keen to hear about your ideas for raising money.

e) Hepatitis Support Group (Manor House Group)

Come and meet members of the recently formed Manor House Group. They will explain who they are and what they are doing to help and support people with haemophilia and hepatitis.

f) Macfarlane Trust

John Williams, the Administrator of the Macfarlane Trust will be available to answer any of your questions about the workings of the Trust.

g) Parent Support Group

The Society has formed a Parent Support working group which will be explaining the Society's plans for increasing support to parents, particularly parents of newly diagnosed children. The group is keen to hear your ideas on what should be done.