

HAEMOPHILIA ACADEMY – INFORMATION FOR POTENTIAL PARTICIPANTS



The Haemophilia Academy is an annual, haemophilia-focused educational event run by experts in haematology. Its aim is to provide specific education and support for haemophilia treaters at an early stage in their careers.

Objectives of the Haemophilia Academy

The Haemophilia Academy aims to:

- provide support to trainee haemophilia treaters to develop their career in haemophilia
- address the perceived and real educational needs of the haemophilia treaters
- improve the management of haemophilia and allied bleeding disorders

Faculty and support

The Haemophilia Academy is led by a distinguished Faculty of six haemophilia experts:

- Professor Claude Négrier (Chair), Lyon, France
- Dr Victor Blanchette, Toronto, Canada
- Dr Keith Hoots, Washington, USA
- Dr Roseline d'Oiron, Paris, France
- Dr Stacy Croteau, Boston, USA
- Dr Margareth Ozelo, São Paulo, Brazil

The Faculty are responsible for planning the programme, selecting participants, developing educational materials and delivering the programme.

Core sponsorship for the Haemophilia Academy is provided as an unrestricted educational grant from Novo Nordisk Health Care AG. Secretariat support is provided by AXON Communications. All candidates are responsible for checking and adhering to local regulations before applying to the Haemophilia Academy. Successful EU applicants should be aware that the value of their participation may be reported by Novo Nordisk under the terms of the EFPIA HCP/HCO disclosure code on transfers of value from pharmaceutical companies to healthcare professionals and healthcare organisations.

Training programme

The Haemophilia Academy will consist of a 4.5-day training course, including a 1-day clinic visit. The aim of this interactive programme is to equip participants with the knowledge and skills that they need to develop their career in haemophilia and to discuss how to apply this information in a way that helps optimise patient care.

The programme will include different types of educational session:

- Keynote lectures (lecture followed by questions)
- Interactive plenary sessions (lecture with interactive discussion and group work)
- Group workshops (10 participants/group)
- Case-discussion and networking sessions
- Panel discussions

The course will be delivered in English and **participants should have a good knowledge of written and spoken English.**

Participants and selection criteria

Participants should be qualified physicians towards the end of their specialty training and should exhibit evidence of a career interest in haemophilia. The Haemophilia Academy will provide them with knowledge and skills they can pass on to their colleagues, including junior trainees.



Eligible candidates should:

- ideally have 3–4 years' experience in haematology
- have a significant focus on and career interest in haemophilia
- be individuals for whom haemophilia patients comprise or are likely to comprise a significant proportion of practice
- be nominated by their academic institution
- be available to attend a 4.5-day course from Monday 17 - Friday 21 October 2022 and to arrive in Edinburgh on Sunday 16 October for a welcome dinner that evening
- be competent in written and spoken English
- Candidates must complete the application form within this pack and have the endorsement of their nominating centre. A letter from the Chair to the head of your institution, introducing the Haemophilia Academy and asking them to endorse your application, is provided towards the end of this document. Numbers are limited to 32; should eligible applications exceed this, places will be allocated by the Faculty based on review and selection of the applications.
- Each application must be accompanied by a letter of personal endorsement from the nominating Centre Director recommending the applicant for the course. Letters of endorsement should confirm the applicant's exposure to haemophilia in the clinical setting and describe their past experiences with patients with haemophilia. A guide for Centre Directors on writing the endorsement letter is included at the end of this document.

Accreditation and endorsement

Accreditation for the Haemophilia Academy course will be from the European Accreditation Council for Continuing Medical Education (EACCME). In 2022, participants who completed the virtual training course and evaluation were awarded 14 credits of education.

The 2022 Haemophilia Academy is endorsed by the Hemostasis and Thrombosis Research Society (HTRS) and is awaiting endorsement from the International Society on Thrombosis and Haemostasis (ISTH).

Notes

1. Due to regulations, US candidates not currently enrolled in a fellowship programme will not be eligible for funding from the Haemophilia Academy.
2. **All successful candidates are responsible for compliance with local laws and regulations regarding financial support to attend the Haemophilia Academy.**

HAEMOPHILIA ACADEMY – DRAFT COURSE AGENDA



Haemophilia Academy

N.B. agenda below is based on 2019 programme and may be subject to change

Day 1: Monday 17 October		
Keynote lecture	The haemostatic system and responses to vascular injury	Dr Hoots
Keynote lecture	Guest speaker session TBC	Guest speaker (TBC)
Keynote lecture	Inhibitors	Margareth Ozelo
Workshop	Three sessions run in parallel*	All Faculty
Keynote lecture	Prophylaxis	Dr Blanchette
Day 2: Tuesday 18 October		
Interactive plenary	Pathogenesis and natural history of haemophilia	Dr Hoots
Keynote lecture	Women with bleeding disorders	Dr d'Oiron
Interactive plenary	von Willebrand Disease	Stacy Croteau
Workshop	Three sessions run in parallel*	All Faculty
Keynote lecture	Rare bleeding disorders	Dr Blanchette
Day 3: Wednesday 19 October		
Interactive plenary	Surgery	Prof. Négrier
Workshop	Three sessions run in parallel*	All Faculty
Interactive plenary	Guest speaker session TBC	Guest speaker (TBC)
Networking	Poster session and working lunch**	
Day 4: Thursday 20 October – Edinburgh Comprehensive Haemophilia Care Centre		
Tour of the Centre		Clinic staff
Plenary sessions: Physiotherapy: joint assessment, organisation of care, Radiology		Clinic staff
Laboratory demonstrations OR clinical case sessions (run in parallel)		Lab staff / clinic staff
Networking		Poster session and working lunch**
Day 5: Friday 21 October		
Interactive plenary	Pregnancy and delivery	Dr d'Oiron
Keynote lecture	Clinical trials and future therapies	Prof. Négrier
Keynote lecture	New non-factor replacement therapies for haemophilia	Stacy Croteau
Self-assessment and follow-up		

*Workshop sessions: platelet disorders, inhibitor management and management of older patients.

**Meals and refreshment breaks will provide other opportunities for networking.

LOGISTICS INFORMATION



Haemophilia Academy

Dates

The 4.5-day training course will take place on 17-21 October 2022 with participants expected to arrive in Edinburgh on Sunday 16 October for a welcome dinner that evening. Participants are required to attend all 4.5 days. You are encouraged to clear these dates in your calendar as early as possible.

Venue

The meeting will be held at the Surgeons' Hall Complex and the Edinburgh Haemophilia Comprehensive Care Centre in Edinburgh, UK.

Financial support

Core sponsorship for the Haemophilia Academy is provided as an unrestricted educational grant from Novo Nordisk Health Care AG. Individual costs are covered as indicated in the table below (see also additional notes below table).

	Covered by the Haemophilia Academy	Covered by the participant
Travel to Edinburgh (e.g. air or rail transport) ¹		✓ ^{1,2}
Ground transportation to and from the venue (e.g. from airport or railway station)	✓	
Accommodation		✓ ¹⁻³
Meals (breakfast, lunch, dinner) and coffee breaks	✓	
Out-of-pocket expenses (e.g. transportation in home country)		✓
Incidentals (e.g. hotel charges for telephone calls or dry cleaning, bar bills)		✓

Notes

- Participants will be able to apply to the local Novo Nordisk affiliate or other sources for a grant to cover air/rail travel expenses and accommodation in Edinburgh. Local regulations will apply, and receipts and boarding cards will be needed. Should your application to attend the Haemophilia Academy course be successful, you will be provided with contact details for the relevant Novo Nordisk staff member and information on how to apply. Travel costs will only be reimbursed if the participant has attended the meeting (i.e. cancellation costs are not covered). Please do not make any travel plans until your place on the course has been confirmed. **All successful candidates are responsible for compliance with local laws and regulations regarding financial support to attend the Haemophilia Academy. Successful EU applicants should be aware that the value of their participation in the course may be reported by Novo Nordisk under the terms of the EFPIA HCP/HCO disclosure code on transfers of value from pharmaceutical companies to healthcare professionals and healthcare organisations. For further information on this please contact the Haemophilia Academy Secretariat.**
- Due to regulations in the US, only those US candidates who are currently enrolled in a fellowship programme will be eligible to apply for funding from the Haemophilia Academy. **Successful US applicants should be aware that the value of their participation in the course may be reported by Novo Nordisk under the terms of the 'Physician Payment Sunshine Act'.**
- For some participants it may not be possible to return home on the final day of the meeting because of flight schedules; in this case, 5 nights' accommodation will be required.

HAEMOPHILIA ACADEMY 2022

APPLICATION FORM CONTINUED



11. Number of years' relevant experience in **haematology** i.e. managing the clinical care of patients or having done research in haematology, forming a significant part of practice or training:

- <1 year 1–2 years 3–4 years 5 years >5 years

12. Number of years' relevant experience specifically in clinical care or research in **haemophilia** i.e. managing the clinical care of patients or having done research in haemophilia, forming a significant part of practice or training:

- <1 year* 1–2 years 3–4 years 5 years >5 years

*If <1 year, please specify in months: _____ months

13. What percentage of your time in total is currently dedicated to **haemophilia**? _____ %

14. How many different patients with haemophilia and/or severe bleeding disorders are seen at your centre per year (approximately)?

15. How many patients with haemophilia and/or severe bleeding disorders have you helped to manage in the last 12 months (approximately)?

16. Please confirm your role at your place of work?

- Clinician Researcher Clinical Researcher Other please specify:

17. If you answered Clinical Researcher above, please specify the ratio of your time spent on clinical practice vs research?

18. **For US applicants**, are you currently enrolled in a fellowship programme?

- Yes No

19. **For US applicants** enrolled in a fellowship programme, how many years of fellowship training have you completed?

- <1 year 1–2 years 3–4 years >4 years

HAEMOPHILIA ACADEMY 2022

APPLICATION FORM CONTINUED



Haemophilia Academy

20. Have you obtained your specialist qualification?

Yes

No

If **yes**, when it was obtained?

If **no**, when do you expect to obtain it?

What is the qualification?

21. Have you presented on haematology at congresses or published in the field?

Yes

No

22. Have you presented on haemophilia or rare bleeding disorders at congresses or published in the field?

Yes

No

If yes to either of the questions above, please provide details on a separate sheet (unless listed in attached CV)

23. What are your relevant haematology or haemophilia research interests?

Please give details of the specific areas of research that you are interested in limiting your answer to about 200 words.

24. If you have only been working in haemophilia for a short time, please explain what you have done in your work to date and how you see the focus of your clinical interest developing?

Please limit your answer to about 100 words.

HAEMOPHILIA ACADEMY 2022

APPLICATION FORM CONTINUED



25. Are you a member of any professional societies?
If so, please give details limiting your answer to about 100 words.

26. Please tell us how you expect to benefit from participation in the Haemophilia Academy.
Please limit your answer to about 200 words.

27. Please provide an explanation of your future career plans in haemophilia.
Please limit your answer to about 200 words.

HAEMOPHILIA ACADEMY 2022

APPLICATION FORM CONTINUED



28. Please provide an explanation of how you think your participation in the course will affect clinical practice and patient care in your home country.
Please limit your answer to about 200 words.

29. Please tell us what insights you might contribute (suggest 1/2 points) to the Haemophilia Academy programme if you are selected to attend, e.g. PhD expert knowledge in a particular area, case experience of rare bleeding disorders, or a specific country perspective such as working in a resource constrained clinical setting.
Please limit your answer to about 200 words.

HAEMOPHILIA ACADEMY 2022

APPLICATION FORM CONTINUED



30. Are you available to attend the course in Edinburgh on 17-21 October 2022, with arrival on 16 October?

- Yes No

31. How did you hear about the Haemophilia Academy?

- Via a senior colleague who received a letter
- I picked up a leaflet from a congress

If **yes**, at which congress did you pick up your leaflet?

- EAHAD
- HTRS
- ISTH
- A recommendation from a previous participant
- I visited the Haemophilia Academy website
- Other; please specify:

32. Before applying for the Haemophilia Academy, did you visit www.haemophiliaacademy.com?

- Yes No

HAEMOPHILIA ACADEMY 2022

APPLICATION FORM CONTINUED



In order to participate in presentations and discussions, all Haemophilia Academy attendees **must** be able to both **understand and communicate clearly in English.**

Please describe your level of **written English** (e.g. native language, fluent, school level, basic level):

Please describe your level of **spoken English** (e.g. native language, fluent, school level, basic level):

Applicant signature:

Endorsement by nominating centre

Applications ***must*** be countersigned electronically by the Director (or equivalent) of the nominating centre/fellowship programme.

Nominating centre:

Signature:

Name and job title:

Please rate the candidate's level of written and spoken English:

Competent

Not competent

Please submit your completed application using the 'upload' link on the Haemophilia Academy website, which should **include your brief CV/resumé and a letter of endorsement from your Centre Director**, by **Friday 15 July 2022**. Applications received after the deadline will not be considered.

Completed applications should be uploaded to the 'apply' section of the Haemophilia Academy website <https://haemophiliaacademy.com/apply/> using the 'upload' link. **Incomplete applications will not be considered.**

HANDLING PERSONAL INFORMATION



Haemophilia Academy

Please submit this form along with your completed application.

We respect and are committed to protecting your privacy. The Privacy Notice below lets you know how the personally identifying information (“personal information”) you provide us with when applying to the Haemophilia Academy is processed and used. We ask if you are in agreement to provide your consent to the storage and disclosure of your personal information for use in managing the Haemophilia Academy.

Consent

By consenting to this privacy notice you are giving us permission to process your personal data specifically for the purposes identified below.

Your consent is required for the Haemophilia Academy to process your personal data. Where we are asking you for sensitive personal data we will always tell you why and how the information will be used. You may withdraw consent at any time by contacting us at: haemophilia.academy@axon-com.com

Please read the Privacy Notice below and indicate your consent by ticking the boxes:

- I confirm that I have read the Privacy Notice outlined.
- I confirm that I agree with the Privacy Notice and give my consent for Haemophilia Academy to process my personal data specifically for the purposes identified in managing the Haemophilia Academy.

HAEMOPHILIA ACADEMY PRIVACY NOTICE

Collection, Use and Disclosure of Personal Information

By applying to the Haemophilia Academy, you choose to provide personal data including your name, e-mail address, telephone number and curriculum vitae to us as part of the application process, submitted to the Secretariat at haemophilia.academy@axon-com.com.

Haemophilia Academy will only use your personal details for the purposes of managing the Haemophilia Academy. This includes sharing applications with the Haemophilia Academy Faculty for their review, scoring and selection; sharing names and contact details with Novo Nordisk and affiliates (where applicable) in order to provide support for travel and accommodation to the training; retaining applicant details to cross check for repeat applicants; retaining alumni details to keep in touch and inform about future events/activities.

Haemophilia Academy will not sell, share or rent your personal information to others except with your consent; when we need to share the information to provide a service, you have requested; or to enable a third party to provide services to us and then only to provide those services. We also will disclose personal information to enforce our rights, to prevent fraud or when required by law, judicial process or other legal order to do so.

Where is information held?

Data will be stored in a range of different places, including our secure server, a secure section of the Haemophilia Academy website and via email.



Haemophilia Academy

Retention period

Haemophilia Academy will store personal data for 15 years for the purposes of retaining applicant details to cross check for repeat applicants and informing Haemophilia Academy alumni about future events/activities.

E-mail Communications

You will receive email correspondence from us regarding Haemophilia Academy updates and related information for the training course as well as future alumni events.

Accessing and Updating Your Personal Information

You can ask us what information we hold about you by contacting us on haemophilia.academy@axon-com.com. Please keep your information up-to-date by letting us know of any changes.

Your Rights

As a data subject, you have a number of rights. At any point while we are in possession of or processing your personal data, you, the data subject, have the following rights:

- Right of access – you have the right to request a copy of the information that we hold about you.
- Right of rectification – you have a right to correct data that we hold about you that is inaccurate or incomplete.
- Right to be forgotten – in certain circumstances you can ask for the data we hold about you to be erased from our records.
- Right to restriction of processing – where certain conditions apply to have a right to restrict the processing.
- Right of portability – you have the right to have the data we hold about you transferred to another organisation.
- Right to object – you have the right to object to certain types of processing such as direct marketing.
- Right to object to automated processing, including profiling – you also have the right to be subject to the legal effects of automated processing or profiling.
- Right to judicial review: in the event that Haemophilia Academy refuses your request under rights of access, we will provide you with a reason as to why. You have the right to complain

If you would like to exercise any of these rights, please contact the Haemophilia Academy Secretariat at: haemophilia.academy@axon-com.com. If you believe that the organisation has not complied with your data protection rights, you can complain to the Information Commissioner.

Security

We maintain physical, electronic and procedural safeguards intended to protect against loss, misuse or unauthorized access to your personal information. Except as otherwise stated in this Privacy Notice, we restrict access to your personal information to those employees and contractors who reasonably need to come into contact with that information to provide information to you, and they may use it only for that purpose.

Changes to this Privacy Notice

We may change our Privacy Notice from time to time so please check back periodically on the Haemophilia Academy website (<http://haemophiliaacademy.com>).

This Privacy Notice was last updated in January 2019.

Contacting Us

If you have any questions about this **Privacy Notice** please contact the Haemophilia Academy Secretariat at: haemophilia.academy@axon-com.com

HAEMOPHILIA ACADEMY – INVITATION TO NOMINATE A JUNIOR COLLEAGUE



Dear Centre Director/Fellowship Programme Director

Haemophilia Academy, 17-21 October 2022

I am delighted to introduce the Haemophilia Academy – a faculty-driven, haemophilia-focused initiative that seeks to help fulfil the educational needs of haematologists intending to develop a career in haemophilia and bleeding disorders.

The Haemophilia Academy will be a 4.5-day course, with 3.5 days of interactive tuition on a range of clinical and non-clinical topics coupled with a 1-day clinic visit. It will take place from 17-21 October, in Edinburgh, UK, with participants arriving on Sunday 16 October for the welcome dinner that evening. The course is being developed and delivered by an international Faculty of six haemophilia experts. It will be attended by approximately 32 haematologists from around the world.

On behalf of the Faculty, I would like to invite you to nominate one trainee haematologist from your Centre to participate in the Haemophilia Academy course. We aim to support individuals towards the end of their training who have shown evidence of a career interest in haemophilia and bleeding disorders.

We ask you formally to endorse the application by counter-signing the application form attached and writing a letter of endorsement, describing the applicant's experiences with haemophilia in the clinical setting and recommending why they would make a suitable participant. A brief guide to writing the endorsement letter is attached.

The application pack included with this letter provides:

- information on the Haemophilia Academy, including a draft course agenda
- an application form and Privacy Notice for potential participants to complete.

There are only 32 places available at the Haemophilia Academy this year; we are therefore asking you to **nominate only one suitable individual to apply**. Should there be more applications than places, the Faculty will review the applications and select successful participants on the basis of their applications' merit. You will appreciate that we would like to complete the selection process in good time to allow participants to clear the training meeting dates in their diaries. We have therefore set a deadline for applications for **15 July 2022**; successful applicants will be informed as soon as possible after the deadline and once the Faculty selection process is complete.

Core sponsorship for the Haemophilia Academy is provided as an unrestricted educational grant from Novo Nordisk Health Care AG. Additional sponsorship provided as an unrestricted educational grant from Instrumentation Laboratory. Secretariat support is provided by AXON Communications. Accreditation for the Haemophilia Academy course will be from the European Accreditation Council for Continuing Medical Education (EACCME). In 2021, participants who completed the course and evaluation were awarded 14 credits of education.

We look forward to receiving an application from your centre. If there are any questions, I should be pleased to hear from you or a potential applicant from your centre.

With best wishes,

Professor Claude Négrier, Chair of the Haemophilia Academy
Email: haemophilia.academy@axon-com.com

HAEMOPHILIA ACADEMY – GUIDANCE FOR THE ENDORSEMENT LETTER



The endorsement letter is an important part of a candidate's application to the Haemophilia Academy. It allows you, as the Centre Director, the opportunity to support the application and express why you feel the applicant should be considered for a place at the Haemophilia Academy.

Whilst a strong and detailed application is the most important factor in selecting candidates, your personal input regarding the career opportunities and the benefit of training can be invaluable to the Faculty as they make their selection.

The following information is a guide to the type of information you may wish to include in your endorsement letter:

- The nature and length of your professional relationship with the applicant
- The applicant's experience of haemophilia and bleeding disorders in the clinical setting
- The nature of the applicant's work at your centre
- An explanation as to why you feel the applicant is suitable for the Haemophilia Academy, including how attendance would benefit the applicant and optimise patient care
- Details of the applicant's relevant awards, scholarships or prizes
- How you envisage the applicant progressing in their career following attendance at the Haemophilia Academy
- What benefits you feel the applicant's participation in the Haemophilia Academy would bring to the care of people with haemophilia in your region

**Please note, if your candidate has not yet had a traditional career in haemophilia but will in future, please provide additional documentation to support this*

The endorsement letter must be signed by the director (or equivalent) of the nominating centre.

If you have any further questions about writing the endorsement letter, or require additional clarification of what is required, please contact the Haemophilia Academy Secretariat at AXON Communications (haemophilia.academy@axon-com.com).