



**CHATELET**  
1706



**HERSCHEL**  
1750



**SOMERVILLE**  
1780



**ANNING**  
1799



**LOVELACE**  
1815



**MEITNER**  
1878



**BALL**  
1892



**HODGKIN**  
1910



**POOL**  
1919



**FRANKLIN**  
1920



**NILSSON**  
1923




**YOU**

THE FIRST  
EUROPEAN CONFERENCE ON  
**WOMEN AND BLEEDING DISORDERS**

DIAGNOSIS | TREATMENT | CARE | PLANNING | COMMUNITY | PSYCHOSOCIAL

24 - 26 MAY 2019 | LE MÉRIDIEN HOTEL, FRANKFURT

[www.ehc.eu](http://www.ehc.eu) | [#WBDEHC](https://twitter.com/WBDEHC)

A photograph of Roberta Smith, a woman with short blonde hair and glasses, smiling while fishing. She is holding a fishing rod and reel, and the background shows a calm lake with hills in the distance under a blue sky with scattered clouds.

**Roberta Smith**  
Living with VWD

## Driven by **Our Patients**

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CSL Behring is proud to work together with the European Haemophilia Consortium to help ensure patients' needs are met.



# WELCOME LETTERS

## MESSAGE FROM THE PRESIDENT OF THE EUROPEAN HAEMOPHILIA CONSORTIUM

Dear delegates, Dear colleagues,

On behalf of the European Haemophilia Consortium (EHC), I warmly welcome you to the first EHC Conference on Women and Bleeding Disorders.

In the past few years, the EHC has increased our focus and activities to better represent and serve patient populations, who were traditionally underserved within the haemophilia community, including women affected by bleeding disorders.

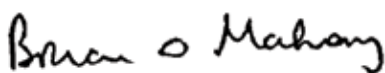
In 2015, the EHC ran a first pre-conference workshop ahead of our scientific conference in Belgrade, Serbia on *"Starting a European conversation for women with bleeding disorders."* The title of the workshop was quite prophetic as, thanks to a group of dedicated volunteers from across Europe, the EHC was able to exponentially increase our focus on women over the years from specific sessions in our scientific conferences, to inclusion in our youth debates and Leadership Conference, to this stand-alone conference this weekend. Our focus on women and bleeding disorders has never been more prominent.

2017 was a pivotal year for women and bleeding disorders in our Consortium. Firstly, we surveyed our members, patient associations, haemophilia treatment centres and women with bleeding disorders on issues faced by this community. The responses were astonishing with over 700 responses detailing the reality of what it means for a woman to live with a bleeding disorder in Europe. The responses were analysed and published in *Haemophilia* and I invite you to read this ground-breaking article, which you will find in your conference packs.

The second significant milestone of 2017 was the creation of a Committee for Women and Bleeding Disorders, which since then, has eight strong women meeting every month to advance their cause: creating awareness, recognition, support and education about, and for women in the bleeding disorder community at European level. This conference is their highest achievement and I commend them for their hard work.

I hope that you will be able to learn, share your experiences and best practices and hopefully create long-lasting connections with volunteers from across Europe that will enable you to further the cause of women with bleeding disorders in your country.

Sincerely yours,



**Brian O'Mahony**  
President, EHC

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## SPONSORS

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### PLATINUM Sponsor

**CSL Behring**  
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### BRONZE Sponsor

 **novo nordisk®**

*Sponsorship does not cover any social events.*

# WELCOME LETTERS

## MESSAGE FROM THE EHC WOMEN AND BLEEDING DISORDERS COMMITTEE

Dear friends, Dear colleagues,

The EHC Women and Bleeding Disorders Committee is delighted to welcome you all to this first conference dedicated to women and bleeding disorders. Our journey has been long and the road ahead towards adequate access to diagnosis, treatment and care is still far but we believe that this first conference is a huge milestone. We are so thrilled to bring together close to 150 delegates including patient representatives from nearly 30 countries!

As issues faced by women with bleeding disorders are many and not often talked about, it was a real challenge to put together the scientific programme of this conference. There was so much that our members asked us to talk about and unfortunately only two days to do so. However, thanks to the support of the Conference Programme Committee, we were able to come up with a programme, which encompasses different topics, which we hope you will find useful both for yourselves and for the work you carry out in your countries.

We will start the conference on Friday with a refresher on genetic transmission (plenary 1) then continue with an overview of bleeding disorders affecting women (plenary 2). On Saturday we will look both at gynaecological (during a symposium kindly donated to the EHC by CSL Behring) and non-gynaecological issues (plenary 4) for women with bleeding disorders as well as how to tackle the most challenging issue for women with bleeding disorders, managing monthly menses (plenary 3). On Sunday in the everyday issues (plenary 5) we will look at the impact of bleeding disorders on quality of life and how to tackle psychosocial issues. Throughout the conference we have organised two breakout sessions with two streams: one on family planning and one on how to best gain support from both National Member Organisations (NMOs) and haemophilia treatment centres.

Finally, we are delighted to be able to show you another one of our proudest achievements and what we believe will be a very strong advocacy tool: a movie on women with bleeding disorders. For this we would like to thank the wonderful director Mr Goran Kapetanovic for making this movie but most of all we wish to thank all of the women who were brave enough to come in front of the camera to tell their story in a very intimate way. We are certain that this movie will help us raise awareness amongst a greater audience about issues faced by women with bleeding disorders.

We are also so delighted to have at this conference, colleagues from the United States as well as representatives from the European Association for Haemophilia and Allied Disorders (EAHAD), a European organisation representing healthcare professionals specialised in haemophilia and other rare bleeding disorders. Since 2018, this association has created a multi-disciplinary committee of healthcare professionals specialised in women with bleeding disorders and we were honoured to be invited to join this group and to be able to give a patient perspective to healthcare professionals as well as to update them on our activities. Finally, we are delighted to have representatives from the World Federation of Hemophilia (WFH) amongst our delegates and we warmly invite you to join the symposium that we have donated to them, which will be taking place on Friday. Last but not least, many thanks to our corporate sponsors who helped us in making this event possible.

We realise that this is a busy programme and therefore we have built in frequent and long coffee breaks. We also invite you to meet us on Friday night for an ice-breaker, which we hope will allow you to connect with other delegates and then on Saturday night for our *"Bloody Mary's session."*

I also invite you to visit the EHC stand where you will find more information about the activities of the EHC and our Committee for Women and Rare Bleeding Disorders, during each coffee break, you will be able to meet EHC staff and representatives from this committee, as well as finding out more about what we do and how you too can start a committee for women and bleeding disorders in your country.

Through this conference we hope that you will not only gain more knowledge about women with bleeding disorders but also create a network of dedicated women across Europe who can share knowledge and best practices and support each other!

A warm welcome from all of us at EHC! We are so glad you came!

**The members of the EHC Women and Bleeding Disorders Committee**

# COMMITTEES

## CONFERENCE ORGANISERS

» European Haemophilia Consortium

## CONFERENCE ORGANISING COMMITTEE

- » Amanda Bok
- » Roseline d'Oiron
- » Evelyn Grimberg
- » Rezan Kadir
- » Declan Noone
- » Ana Pastor
- » Flora Peyvandi
- » Debra Pollard
- » Laura Savini
- » Naja Skouw-Rasmussen

# INVITED SPEAKERS & CHAIRS

- |                           |                 |
|---------------------------|-----------------|
| » Prof Angelika Batorova  | Slovakia        |
| » Dr Eugenia Biguzzi      | Italy           |
| » Dr Roseline d'Oiron     | France          |
| » Dr Alison Dougall       | Ireland         |
| » Evelyn Grimberg         | The Netherlands |
| » Dr Rezan Kadir          | United Kingdom  |
| » Marie Lahn Røhmcke      | Norway          |
| » Dr Michelle Lavin       | Ireland         |
| » Ana Pastor              | Portugal        |
| » Debra Pollard           | United Kingdom  |
| » Olivia Romero-Lux       | France          |
| » Naja Skouw-Rasmussen    | Denmark         |
| » Liora Tevet             | Israel          |
| » Anna Tollwé             | Sweden          |
| » Dr Ioannis Tsimpanakos  | United Kingdom  |
| » Minette van der Ven     | The Netherlands |
| » Dr Karin van Galen      | The Netherlands |
| » Dr Sylvia von Mackensen | Germany         |

# REGISTRATION

The registration desk will be located in the Foyer of the Le Méridien Hotel and will be open on:

**Friday 24 May** 10.00 – 19.00

**Saturday 25 May** 07.30 – 13.30

Delegate registration fee includes:

- » Access to all sessions and scientific programme
- » Access to the exhibition
- » Welcome reception and buffet dinner on Friday
- » Social event and buffet dinner on Saturday
- » Morning and afternoon refreshments during official breaks
- » Lunch on Friday, Saturday and Sunday

# CONFERENCE SECRETARIAT



**CONFERENCE ORGANISERS**

COMPLETE CONFERENCE MANAGEMENT

EHC Conference on Women and Bleeding Disorders  
Conference Organisers

20C The Courtyard  
Castle street, Dalkey, Co. Dublin, Ireland

**T.** +353-1-2859033

**E:** [info@conferenceorganisers.ie](mailto:info@conferenceorganisers.ie)

**w:** [www.conferenceorganisers.ie](http://www.conferenceorganisers.ie)

[www.ehc.eu](http://www.ehc.eu)

## FRIDAY 24 MAY 2019

08.00 – 12.00	Exhibition, Posters and Registration Set-Up		Unlock 1 + 2
10.00 – 12.00	Arrival / Registration / Lunch		Foyer
11.50 – 12.00	Welcome to the Conference and introduction to the work of EHC Amanda Bok		Culture 1 + 2 + 3
12.00 – 13.30	Plenary 1	Bleeding disorders in girls and women (setting the scene) Minette van der Ven	
12.00 – 12.30	Women and Bleeding Disorders in Europe: Results from EHC Survey Naja Skouw-Rasmussen		
12.30 – 13.00	An overview of rare bleeding disorders in women Michelle Lavin		
13.00 – 13.30	Q&A and discussions		
13.30 – 14.00	Coffee break		Unlock 1 + 2
14.00 – 16.00	Plenary 2	Genetics 101 – Understanding transmission & genetic testing of inherited bleeding disorders Rezan Kadir	Culture 1 + 2 + 3
14.00 – 14.20	Haemophilia – inheritance, carrier detection Eugenia Biguzzi		
14.20 – 14.40	RBD – transmission – inheritance and carrier detection Eugenia Biguzzi		
14.40 – 15.00	VWD - Transmission, inheritance and detection Karin van Galen		
15.00 – 15.30	Prenatal testing and diagnosis Rezan Kadir		
15.30 – 16.00	Q&A and discussions		
16.00 – 16.30	Coffee break		Unlock 1 + 2
16.30 – 18.00	WFH Symposium	Raising awareness globally for women with inherited bleeding disorders	Culture 1 + 2 + 3
19.00 – 19.30	Welcome reception and ice-breaker		Unlock 1 + 2
19.30 – 21.30	Welcome Dinner		Cloud & Legacy



# SATURDAY 25 MAY 2019

08.00 – 09.30	Plenary <b>3</b>	Management of heavy menstrual bleeding Michelle Lavin	Culture 1 + 2 + 3
08.00 – 09.00	Preparing for menarche: Developing a treatment and management plan for heavy periods – including treatment options and how to approach and prepare for adolescence Panel discussion between: Rezan Kadir, Roseline d'Oiron, Anna Tollwé, Debra Pollard, Sylvia von Mackensen		
09.00 – 09.30	Q&A and discussions		
09.30 – 10.00	Coffee Break		Unlock 1 + 2
10.00 – 11.30	CSL Behring Symposium	Other gynaecological issues in WBD Symposium donated to EHC	Culture 1 + 2 + 3
11.30 – 12.00	Coffee Break		Unlock 1 + 2
12.00 – 13.30	Breakout sessions		
13.30 – 14.30	Lunch		Cloud & Legacy
14.30 – 16.00	Plenary <b>4</b>	Non-gynaecological issues in women with bleeding disorders Olivia Romero-Lux	Culture 1 + 2 + 3
14.30 – 15.00	Detection & management of iron deficiency and anaemia in WBD's Eugenia Biguzzi		
15.00 – 15.30	Oral care in WBD Alison Dougall		
15.30 – 16.00	Q&A and discussions		
16.00 – 16.30	Coffee break		Unlock 1 + 2
16.30 – 18.00	Screening of Movie "Women and Bleeding Disorders"		Culture 1 + 2 + 3
18.30 – 19.30	Bloody Mary's Session		Culture 1 + 2 + 3
19.30 – 21.30	Dinner		Cloud & Legacy

# SUNDAY 26 MAY

08.00 – 09.30	Plenary <b>5</b>	Everyday issues Roseline d'Oiron	Culture 1 + 2 + 3
08.00 – 08.30	Impact of bleeding disorders on quality of life Naja Skouw-Rasmussen		
08.30 – 09.00	Psycho-social issues Debra Pollard		
09.00 – 09.30	Q&A and discussions		
09.30 – 10.00	Coffee Break		Unlock 1 + 2
10.00 – 11.30	Breakout sessions		
11.30 – 12.00	Coffee Break		Unlock 1 + 2
12.00 – 13.00	Closing session Amanda Bok		Culture 1 + 2 + 3
12.00 – 12.40	Closing panel Rezan Kadir, Roseline d'Oiron, Debra Pollard and Naja Skouw-Rasmussen		
12.40 – 13.00	Evaluations and feedback Laura Savini and Amanda Bok		
13.00 – 14.00	Lunch and departures		Cloud & Legacy

# SYMPOSIA PROGRAMMES

Culture 1+2+3 rooms

## FRIDAY 24 May 2019

**16.30-18.00** World Federation of Hemophilia (WFH) Symposia  
*Raising awareness globally for women with inherited bleeding disorders*  
 Presentation followed by panel discussions with representatives from the Latvian, Swedish and Slovak National Member Organisations (NMOs).


**WFH**

WORLD FEDERATION OF HEMOPHILIA  
 FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
 FEDERACIÓN MUNDIAL DE HEMOFILIA

## SATURDAY 25 May 2019

**10.00-11.30** CSL Behring Symposium donated to EHC  
*Other gynaecological issues in WBD*  
 Chairs: Evelyn Grimberg and Ana Pastor

**10.00 – 10.15** **Surgery** Angelika Batorova

**10.15 – 10.30** **Ovulation bleeding and ovarian cysts** Karin van Galen

**10.30 – 10.45** **Quality of life in relation to gynaecological bleeding**  
 Sylvia von Mackensen

**10.45 – 11.00** **Pain management for women with rare bleeding disorders – focus on pelvic pain** Ioannis Tsimpanakos

**11.00 – 11.15** **Preparing for surgery – Patient Perspective** Evelyn Grimberg

**11.15 – 11.30** **Q&A**

## CSL Behring

Biotherapies for Life™

# BREAKOUT SESSIONS PROGRAMME

## STREAM 1: FAMILY PLANNING

Culture 1+2+3

### SATURDAY 25 May 2019

**12.00-13.30: Fertility and pregnancy in bleeding disorders**

Moderators: Roseline d'Oiron, Rezan Kadir and Marie Lahn Rømcke

This breakout session will be an open discussion in which participants will be able to freely discuss any issues surrounding fertility and pregnancy in women affected by bleeding disorders.

### SUNDAY 26 May 2019

**10.00-11.30: Management of labour, delivery and neonatal care**

Moderators: Rezan Kadir and Angelika Batorova

This breakout session will be an open discussion in which participants will be able to freely discuss any issues related to the management of labour, delivery and neonatal care in women affected by bleeding disorders.

## STREAM 2: EVERYDAY COPING

Chic and Sparkling

### SATURDAY 25 May 2019

**12.00-13.30: Support from your NMO and peer-to-peer support**

Moderators: Representatives from the French and Dutch NMOs

This breakout session will showcase examples on how to build a peer support group and how to utilise your NMO to raise awareness about and provide support to women with bleeding disorders.

### SUNDAY 26 May 2019

**10.00-11.30: Support from the haemophilia treatment centre**

Moderators: Debra Pollard and Liora Tevet

In this breakout session, moderators will explore how to build dialogue with and ensure that women with bleeding disorders are recognised by local haemophilia treatment centres. This breakout session will be an open discussion in which participants will be able to freely engage with moderators and other participants.



JOIN US FOR THE PREMIERE  
SCREENING OF THE MOVIE

# ***“WOMEN AND BLEEDING DISORDERS”***

**SATURDAY, 25 MAY 2019**

16.30 - 18.00

CULTURE 1+2+3

- 16.30-16.40** Movie introduction  
(Goran Kapetanovic, Director & Naja Skouw-Rasmussen, Chair EHC WBD Committee)
- 16.40-17.40** Movie screening
- 17.40-17.55** Q&A  
(Goran Kapetanovic, Ana Pastor, Tatjana Markovic and Naja Skouw-Rasmussen)
- 17.55-18.00** Closing and announcing of evening plan  
(Laura Savini)

# EXHIBITION PLAN UNLOCK 1 + 2



## SOCIAL PROGRAMME

### Welcome Dinner

#### **Friday 24 May**

**19:30-20:00** Welcome reception and 'ice-breaker' will take place in the Foyer and Unlock 1 + 2 (exhibition area)

**20:00-21:30** The Buffet Dinner will take place in the Cloud and Legacy

### Conference Dinner

#### **Saturday 25 May**

**18.30-19.30** Bloody Mary's Session will take place in meeting room Culture 1+2+3

**19.30-21.30** Dinner will take place in the Cloud and Legacy



# SPEAKERS



## Angelika Batorova

Director, National Haemophilia Centre, University Hospital Bratislava, Slovakia

Angelika Batorova is the Director of the National Haemophilia Centre, University Hospital Bratislava, Slovakia. She specialised and obtained degrees in internal medicine, haematology and transfusion medicine. In 1992 she obtained her PhD in haemostasis disorders in acute leukemias.

Dr Batorova has been involved in the comprehensive haemophilia care and the Slovakian National Registry of Congenital Bleeding Disorders since 1978. In 1992 she took a half-year fellowship at the New York Blood Centre, USA. She also took another fellowship appointment with the Haemophilia Centre in Tel Aviv, Israel in 1991. In 2004, she was appointed visiting associate professor at the University of Postgraduate Medicine in Bratislava and since 2010 she holds the position of Associate Professor at the Medical School of Comenius University Bratislava. She is currently heading the Department of Haematology and Blood Transfusion at the University Hospital Bratislava.

Dr Batorova is a member of several scientific societies and international working groups.

She has authored and co-authored over 200 publications, and reviewed articles and book chapters. She is a member of the Haemophilia Journal editorial board and serves as a reviewer for numerous international scientific journals.

Dr Batorova served as a member of the Executive Committee of the World Federation of Hemophilia (WFH) from 2006-2010 and as a member of the Medical Advisory Group (MAG) of the European Haemophilia Consortium (EHC) from 2014-2018.



## Eugenia Biguzzi

Consultant Haematologist, IRCCS Fondazione Ca' Granda Ospedale Maggiore Policlinico, Milan, Italy

Eugenia Biguzzi is a Consultant Haematologist at the IRCCS Fondazione Ca' Granda at the Ospedale Maggiore Policlinico in Milan, Italy. She is currently working with Prof Peyvandi in the haemorrhagic outpatient department. Dr Biguzzi graduated in Medicine at the University of Pavia in 1993 and started to work in paediatric onco-haematology. She then moved to Milan to work together with Prof Mannucci on haemostasis.



## Roseline d'Oiron

Clinician Investigator, Reference Centre for Haemophilia and Other Congenital Rare Bleeding Disorders, Congenital Platelets Disorders and von Willebrand disease, Bicêtre Hospital AP-HP – Paris XI University, Le Kremlin-Bicêtre, Paris, France

Roseline d'Oiron is currently a Clinician Investigator at the Reference Centre for Haemophilia and Other Congenital Rare Bleeding Disorders, Congenital Platelets Disorders and von Willebrand disease.

Her research interests are principally in the area of haemophilia (especially molecular mechanisms, inhibitors, immune tolerance, mild/moderate haemophilia and carrier issues) and Glanzmann's thrombasthenia. Dr d'Oiron has served as a member of the steering committee of the national FranceCoag Network on bleeding disorders and continues as advisor of the working group on inhibitors in this registry. She is also a member of the Executive Committee of the European Association for Haemophilia and Allied Disorders (EAHAD). In 2017 she joined the Medical and Scientific Advisory Group (MASAG) of the European Haemophilia Consortium (EHC) to provide expertise in the area of women and bleeding disorders. She also acts as a reviewer for different journals including Blood, The Journal of Thrombosis and Haemostasis and Haemophilia.



## Alison Dougall

Assistant Professor/Consultant, Dental Science, Trinity College Dublin, Ireland

Alison Dougall is a clinical consultant in special care dentistry at the Dublin Dental University Hospital (DDUH). She is also involved in the teaching and training of dentists at Dublin University Hospital at undergraduate, postgraduate and doctorate level. She is the chair of the Clinical Audit Committee. As part of her role at DDUH she provides consultant-led dental clinics within St Vincent's University Hospital and St James's Hospital in Dublin, Ireland.

In 2014, Dr Dougall was elected as a Chair of the Dental Committee of the World Federation of Hemophilia (WFH) and has been invited to be part of the working party advising on the European Principles of Care for people with haemophilia. Dr Dougall is the past president of the Irish Society of Disability and Oral Health and the Editor of the International Association for Disability and Oral Health. She is on the Academic Reference Panel for the Irish Department of Health advising on the new Oral Health Policy for Ireland. In 2017, Dr Dougall joined the Medical and Scientific Advisory Group (MASAG) of the European Haemophilia Consortium (EHC) as a specialist in dental and oral care for people with bleeding disorders.



# SPEAKERS



**Evelyn Grimberg**

Member, EHC Women and Bleeding Disorder Committee, the Netherlands

Evelyn Grimberg is a volunteer from the Dutch Hemophilia Society (NVHP). She has been in the society's youth committee for nine years, including two years as the committee's President. As a member of the committee, she is committed to highlighting the needs of people with rare bleeding disorders. By telling her story she became recognised as a counsel for this special group, especially for women. She has spoken three times at a WFH congress and once at the EHC Conferences, illustrating her work for the Dutch Hemophilia Society and stressing the importance of attention for person with rare bleeding disorders and women with bleeding disorders.

In 2015/2016 she was a member of the project team of the Blood Relatives cycle trip to Stavanger. Together with the team she organised the 1000 km trip from project plan to realisation. She was also one of the cyclists who cycled the 1000 km to raise awareness for bleeding disorders.

In 2016, she set up a women's committee for the Dutch Hemophilia Society. The committee focuses on better education and information for women and bleeding disorders.

She is also a member of the EHC Women and Bleeding Disorder Committee.



**Rezan Kadir**

Consultant obstetrician and gynecologist, Royal Free London, United Kingdom

Prof Rezan Kadir is a Consultant Obstetrician and Gynaecologist with a subspecialty in foetal medicine at the Royal Free Hospital in London, United Kingdom (UK). She is also a Specialist Consultant in women with bleeding disorders at the hospital, and an Honorary Reader with the University College School of Medicine. She has set up a multi-disciplinary clinic in the haemophilia centre at the Royal Free Hospital in London, which is jointly run with a haemophilia specialist, nurse and family counsellor and therapists. This clinic has been unique in providing comprehensive care for women in families with bleeding disorders. She is also leading several clinical and laboratory projects in this field.

Dr Kadir is the Chair of the "*Women Bleed Too*" board of the UK Haemophilia Society, which includes key professionals and women affected by bleeding disorders. The board aims to create a society in which bleeding disorders are a recognised condition among women and appropriate treatment and support are offered to all those diagnosed. She is also a member of several international societies, including the International Society of Thrombosis and Haemostasis (ISTH), World Federation of Hemophilia (WFH), Women Health Issues in Thrombosis and Haemostasis, British Maternal and Foetal Medicine Society, and the International Society of Ultrasound in Obstetrics and Gynaecology, and many others. Her work in the field of women and bleeding disorders has been well recognised internationally and she is regarded as a world expert in the field. Her name was included in the 2009 edition of Who's Who in Medicine and Healthcare 2009-2010.

In 2017, Dr Kadir joined the Medical and Scientific Advisory Group (MASAG) of the European Haemophilia Consortium (EHC) to provide expertise in gynaecology and obstetrics for women with bleeding disorders.

# SPEAKERS



**Marie Lahn Rømcke**

Board Member, Norwegian NMO

Marie is from Oslo, Norway and has Von Willebrand disease. She has been part of the board of the Norwegian Hemophilia Society since 2012 and part of the society since childhood when she used to attend family summer camps. In recent years she has been involved in arranging weekend trips for young adults with haemophilia and participated in weekend gatherings for carriers or women with haemophilia. Marie works with IT and risk management in a Norwegian bank and in her spare time she likes jogging.



**Dr Michelle Lavin**

MB BCh BAO, PhD, MRCPI, FRCPath  
Clinical Lead, iPATH study, Ireland

Dr. Michelle Lavin is a Consultant Haematologist and the Clinical Lead for the Irish Personalised Approach to the Treatment of Haemophilia (iPATH) and Low Von Willebrand in Ireland Cohort studies, based in the Irish Centre for Vascular Biology, RCSI.

She completed her PhD in Trinity College Dublin, which focused on the pathophysiology and clinical impact of Low Von Willebrand Factor (VWF) levels. Her research is centred on inherited bleeding disorders with a particular focus on the impact of bleeding disorders on women. Her work aims to develop insights into the reasons underpinning phenotypic variability to improve clinical outcomes.

She serves a Co-Chair on the International Society on Thrombosis and Haemostasis (ISTH) VWF Scientific Subcommittee and is the project lead for the ISTH Postpartum Haemorrhage in VWD registry.



**Ana Pastor**

Member, EHC Women and Bleeding Disorder Committee, Portugal

Ana Pastor is a member of the Portuguese Hemophilia Association (APH). She is currently the coordinator of the APH Women's Committee and supported the organisation of APH's national Women's Conferences from 2015 to 2017.

Ana also developed several workshops on issues related to women and bleeding disorders. She was also a speaker at several APH events, including its national congress.

In 2017 Ana joined the EHC WBD Committee.



**Debra Pollard**

Lead Nurse, Katharine Dormandy Haemophilia & Thrombosis Centre, Royal Free Hospital, London, United Kingdom

Debra Pollard is the Lead Nurse at the Katharine Dormandy Haemophilia & Thrombosis Centre at the Royal Free Hospital in London, where she has worked since 1991. She has extensive experience in the care of both adults and children with inherited and acquired bleeding disorders and has been involved with caring for those facing many of the challenges from earlier times, as well as at the forefront of the introduction of new and improving treatment and management for these conditions.

Debra is passionate about the pivotal role played by nurses and allied health professionals in the care of people with haemophilia and other inherited/acquired bleeding disorders. She is keen to ensure the continuation of advanced nursing practice in haemophilia and bleeding disorders through appropriate education, training and mentorship and is a joint course leader for "*Contemporary care of people with bleeding disorders*" a course for nurses and allied health professionals, which has replaced previous UK Haemophilia education programmes on which she taught for many years.

She is a member of the Clinical Advisory Group for the UK Haemophilia Society, having served as a trustee from 2005–2012 and is also on the editorial board of the Journal of Haemophilia Practice. She is a Trustee of Haemnet, a charity, which supports health and social care professionals promoting excellent care for people with bleeding disorders.

# SPEAKERS



**Olivia Romero-Lux**

Member, EHC Steering Committee,  
France

Olivia Romero Lux has been volunteering for the French Hemophilia Association for over 18 years, as the Head of the Family Committee for Paris, member of the National Board and National General Secretary. Since 2013, she is an elected member of the Steering Committee of the EHC. Starting in June 2018, she is also in charge of the International Affairs of the AFH.



**Naja Skouw-Rasmussen**

Member, EHC Steering Committee,  
Denmark

Naja Skouw-Rasmussen volunteers at the Danish Haemophilia Society (DHS) where she organises youth meetings, women's weekend and the DHS annual meeting and participates in the Danish project Telemedicine in haemophilia treatment. For the last seven years she has been a member of DHS's board of directors. Whilst dedicating her time to all with bleeding disorders, one issue close to her heart - improving the life for women with a bleeding disorder in terms of diagnosis, treatment options, social acceptance and support.

Naja is a member of the EHC Steering Committee and the Chair of the EHC WBD Committee. Internationally, she has also worked on Young Voices India, a project focusing on supporting and motivating the young leaders with a bleeding disorder in India.

Furthermore, she has actively participated in several WFH conferences, EHC youth workshop, EHC Leadership Conference, and EHC annual meetings.



**Liora Tevet**

Director, EHC Israeli NMO

Liora Tevet has been the Director of the Israeli Haemophilia Association since 2016.



**Anna Tollwé**

Volunteer, Swedish NMO

Anna Tollwé started volunteering for the Swedish Hemophilia Society in 1995. Since then she has been on several committees and task forces. She also was on the national board for 8 years and served as the first female vice chairperson.

Anna has always been passionate about women's issues and in 2007 she co-founded a women's network that later became the Swedish Women's Committee which she is now Chairwoman for. In 2011 she conceptualized a woman project which became a reality in 2015 and was very successful. Anna has VWD type 2 and is also engaged in the work of increasing knowledge about VWD.



**Ioannis Tsimpanakos**

Consultant, Royal Free Hospital,  
United Kingdom

Ioannis Tsimpanakos is a consultant in obstetrics and gynaecology with a special interest in the management of uterine fibroids, endometriosis and other benign gynaecological conditions. He specialises in laparoscopic and hysteroscopic surgery and runs an out-patient hysteroscopy clinic.



# SPEAKERS



## **Minette van der Ven**

Vice-President Finance, EHC,  
the Netherlands

Minette van der Ven is the Vice-President Finance of the European Haemophilia Consortium and she has been in this position since October 2018. Minette has been a member and volunteer of the Nederlandse Vereniging van Hemofilie-Patiënten (NHVP), the EHC Dutch National Member Organisation, since she was a teenager. From 2010 to 2018, she sat on the NHVP board and currently she remains an active volunteer.

Minette has a background in finance and is a chartered accountant.



## **Dr Karin van Galen**

Consultant Haematologist, Utrecht  
University Medical Centre, the  
Netherlands

After graduating in medicine, Karin van Galen trained in the field of internal medicine. She completed her specialisation as a hematologist in 2011 after which she was appointed as Consultant Hematologist at the Department Van Creveldkliniek of the UMC Utrecht. Here she has expanded her clinical experience in the treatment of patients with benign hematological conditions. In addition to patient care Karin van Galen finished her PhD project on joint bleeding in Von Willebrand disease in November 2017 and currently participates in several (inter)national studies on congenital bleeding disorders. She recently started a post-doc research project on pregnancy in inherited bleeding disorders.



## **Dr Sylvia von Mackensen**

PD Dr. rer. biol. Hum.  
Psychologist, Department of Medical  
Psychology, University Medical Centre  
Hamburg-Eppendorf (UKE), Germany

Sylvia von Mackensen is a senior scientist at the Department of Medical Psychology at the University Medical Centre in Hamburg, Germany since 2003.

She received her diploma in Psychology in 1994 from the Catholic University of Eichstätt, Germany, and performed her PhD at the Department of Medical Psychology at the Ludwig-Maximilian University of Munich. She was a visiting scientist at the Haemophilia and Thrombosis Centre in Milan, Italy from 2007-2010. She has done her post-doctoral thesis *"Patient-Reported Outcomes in Haemophilia"* at the University Medical Centre of Hamburg Eppendorf, Germany in 2017.

Since 1999, She is working in the field of haemophilia. Her main research interest is focused on patient-reported outcomes (PRO) related to people with bleeding disorders, especially with haemophilia. She developed several disease-specific PRO measures for the assessment of health-related quality of life, treatment satisfaction, physical functioning and caregiver burden in patients with bleeding disorders such as haemophilia, VWD and ITP.

Sylvia von Mackensen is a member of the Psychosocial Committee of the World Federation of Hemophilia (WFH) since 2004.

She is currently a lecturer in Medical Psychology at the Universities of Hamburg and Homburg/Saar in Germany.



## TRAVEL

### By Plane

Frankfurt am Main Airport is a major international airport located in Frankfurt and serves as the main hub for Lufthansa including Lufthansa CityLine and Lufthansa Cargo as well as Condor and AeroLogic.

### By Bus

Frankfurt is a central crossroads and is served by bus from several national and international cities. The long-distance coaches stop at both the Main Train Station and Frankfurt Airport.

### By Train

Every day over 1,100 trains connect the city with numerous national and international destinations, while more than 700 'S-Bahn' commuter trains take passengers to stops and stations in Frankfurt and the surrounding region. All in all, more than 400,000 travellers pass through Frankfurt Main stations each day.

### Reaching the Hotel

The Le Méridien Hotel is easily reached from the airport via public transportation: just take the city train S8/S9 from the airport in the direction of Offenbach/Hanau – it travels directly to "Frankfurt Hauptbahnhof" in about 20 minutes. Follow the signs directing you to "B-Ebene". Take the exit Baseler Strasse und turn left into Wiesenhuettenstrasse. The hotel is located on the left, directly on Wiesenhuettenplatz.

## LOCAL INFO

### Currency

The currency of Germany is the Euro.

Foreign currencies can be easily exchanged in banks. ATMs can be found in all parts of the city. Cash withdrawals may be made using your credit/debit card. The logos of accepted cards are shown besides the machine. Most internationally recognised bank credit cards are accepted and widely used in all hotels, restaurants and shopping malls where such methods of payment are indicated by the entrance.

### Electricity

In Germany, the power sockets are a standard voltage of 230V with a frequency of 50Hz.

### Country Code and Important Telephone Numbers

Country Code: +49

Emergency Services: 112

### Climate

The average temperatures in May in Frankfurt will be mild, averaging 14-20°C during the day and dropping as low as 9°C during the night.

### Nearest treatment centre

The nearest treatment centre is located at:

Haemophilia Centre Universitätsklinikum Frankfurt Medizinische Klinik III, Haus 31, Theodor-Stern-Kai 7, Frankfurt am Main, Germany, 60590.

**For adults**, please contact Prof. Dr. med. W. Miesbach, Dr. med. S. Gundermann, the responsible doctors.

**Contact: T:** 069/63015051 or 069/63016738

**24 hrs emergency number:** 0160-4764572

**E:** wolfgang.miesbach@kgu.de

**For children**, please contact Prof. Dr. med. D. Schwabe, Dr. med. C. Heller, the responsible doctors

**T:** 069/6301-6334 or -6432

**24 hrs emergency number:** 0172/617 7000

**E:** christine.heller@kgu.de





# GENERAL INFORMATION

## Accommodation

All changes to accommodation reservations must be made through the Conference Secretariat located at the registration desk in the Conference Centre. Delegates must settle any extra charges, i.e. room service, directly with the hotel on departure.

## Badges

All conference delegates will receive their name badge on registration at the conference. Delegates must wear their name badges at all times to ensure admission to the conference activities.

## Certificate of attendance

Certificate of attendance have been included in each registered delegate onsite documents.

## Treatment room

There is no treatment room available during this conference. If you have a medical emergency, please contact directly one of the EHC staff members.

## Coffee breaks

Coffee breaks will be served during the scheduled breaks in the meeting rooms Unlock 1+2 where the exhibition is being held.

## Lunch

Lunch will be served in the Cloud and Legacy meeting rooms.

## Breakfast

For delegates staying at the Le Méridien Frankfurt, breakfast is served at the Breakfast room from **6.30 until 10.30**.

## Cloakroom

There will be clothes rails inside the Plenary and Breakout Rooms. Please note that these rails are not manned.

## Insurance

The Conference Organising Committee, or its agents, will not be responsible for any medical expenses, loss, damages or accidents during the Event. In particular, we would like to draw your attention to the cancellation policy in respect of registration fees and accommodation. In the event that, for whatever reason, the Conference has to be cancelled or postponed, the Organising Committee, and/or its agents, will be responsible only for refund of monies received. We recommend that delegates insure themselves for medical and cancellation charges.

## Internet facilities

Wireless internet access is available in the meeting area. A login will be provided in the meeting area so every guest can access internet free of charge. In the sleeping rooms the internet is also free of charge.

## Conference language

The official language of the conference is English. Simultaneous interpretation will be available in Russian during the conference sessions in the main meeting room, Culture 1+2+3 on Friday, Saturday and Sunday.

## Speaker room

A Speaker Table will be available next to the Registration Table. Please note that we do not have a Speaker Room for this event. If you want to preview your slides, please go to the EHC Office located in the Discovery Room.

## Mobile phones

Delegates must switch off their mobile phones in all meeting rooms during all conference sessions.

## Audio recorders and cameras

The use of personal recorders and cameras is not permitted during the session.

## Twitter

Delegates are invited to tweet during the conference using **#WBDEHC**. Delegates can follow Twitter updates @EHC\_haemophilia.



# WOMEN AND SCIENCE



**EMILIE DU  
CHATELET**

1706

Was a philosopher, mathematician and physicist at a time when few people could read and write. Her translation and commentary on Newton's Principia about the basic laws of physics is still used today.



**CAROLINE  
HERSCHEL**

1750

The first salaried female scientist, Herschel was awarded the Gold Medal of the Royal Astronomical Society (1828). Along with Mary Somerville, Herschel was the first female member of the Royal Astronomical Society.



**MARY  
SOMERVILLE**

1780

Somerville was a mathematician and astronomer and was nominated along with Caroline Herschel to be the first female member of the Royal Astronomical Society.



**MARY  
ANNING**

1799

At a time when women were not allowed to actively engage in the sciences, Anning revolutionised prehistoric palaeontology.



**ADA  
LOVELACE**

1815

An advanced mathematician and writer, Lovelace saw the true potential of "computing machines" and developed algorithms for computers before there were computers. Lovelace is considered one of the world's first computer programmers.



**LISE  
MEITNER**

1878

Meitner was a physicist who led the team that discovered nuclear fission.



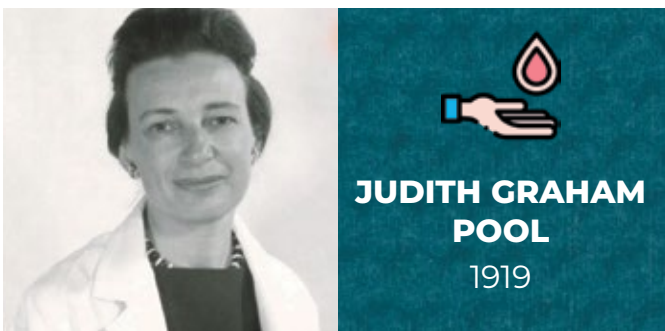
# WOMEN AND SCIENCE



Despite only living to 24 years old, Ball created the 20th century's most effective treatment for leprosy.



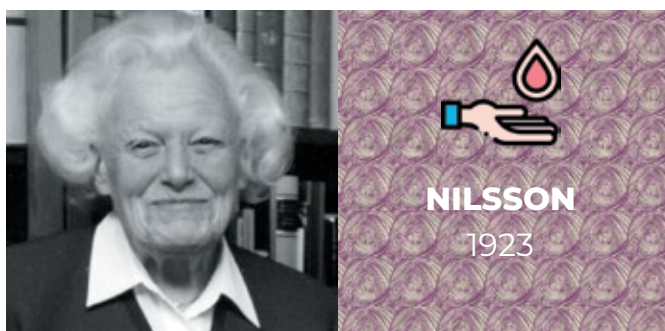
Hodgkin was a chemist who developed protein crystallography. She deciphered the structure of penicillin and insulin. Hodgkin won the Nobel Prize in Chemistry in 1964.



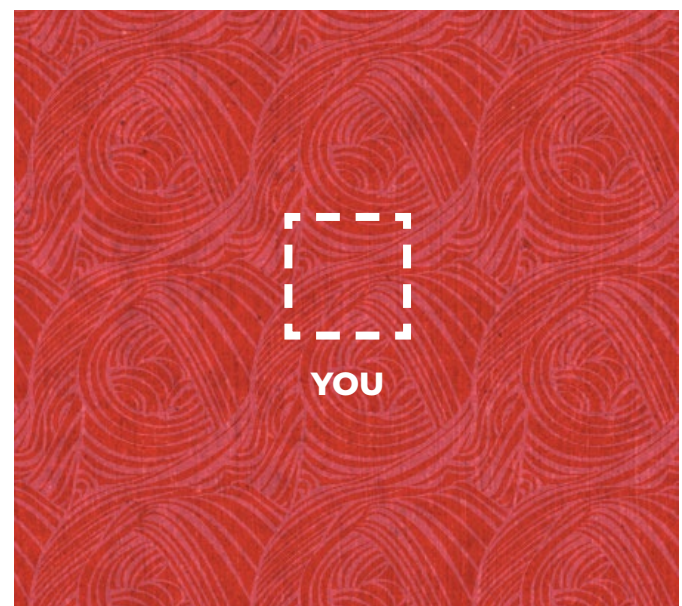
Pool's work on blood coagulation resulted in the development of a cold-insoluble protein fraction of blood plasma, cryoprecipitate, widely used in blood banks. Pool devised and introduced into clinical medicine a preparation containing the lacking protein in patients with haemophilia, which changed treatment in a major way.



Franklin was a chemist and X-ray crystallographer whose work on DNA ultimately led to the discovery of the DNA double helix.



Nilsson was instrumental in the establishment of prophylaxis as the optimal form of treatment for severe haemophilia A and B. The main finding was that prophylaxis started at a very early age (before two years and after the first joint bleed), and this finding, which helped prevent joint damage in boys with severe haemophilia.



# EVERY DAY IS A WINDING ROAD



#ehcelebrate  
1989-2019



## SOCIAL MEDIA



Get social by using the hashtag **#EHCelebrate** and let us know how you will be celebrating EHC's 30th anniversary. Follow our 2019 social media campaign as we launch EHCards, electronic videograms and an art collection culminating in our 30th Anniversary Gala and our vision for 2020.

### #EHCELEBRATE

**Visit our website**

**<https://www.ehc.eu/ehcelebrate/> to send us an EHC card or an electronic videogram.**

Contact Charles Kinney, EHC Communications Officer, [charles.kinney@ehc.eu](mailto:charles.kinney@ehc.eu)



**/EuropeanHaemophiliaConsortium**



**/European-Haemophilia-Consortium**



**@EHC\_Haemophilia**



**/EHCTVChannel**