Welcome to the European Haemophilia Consortium Conference 2019
4-6 October 2019 | Skopje | North Macedonia

www.ehc.eu
#EHC2019
Welcome to the EHC Conference Youth Debate!
As a well-established tradition in the EHC Annual Conference, the Youth Debate has been amongst the most popular sessions in the conference programme. The concept of the Youth Debate is to bring young and dynamic voices into discussion with esteemed figures in the haemophilia community, through a for-and-against debate on key issues.

2018 saw a slightly refreshed format to our Youth Debate, with two debates taking place with youth & established leaders in tandem presenting on both sides. This new format, we hope you agree, encouraged more active participation and high energy from participations in the room! So for EHC Conference 2019, we decided this successful formula must be kept.

With the treatment landscape and the needs of patients changing so quickly in our community, our debates in 2019 will focus on the future and what some of these incredible changes mean for our NMOs and patients – these are themes that are increasingly important for the EHC community. The debates will focus on:

Debate 1: Adversity bred leadership: Will we have commitment from future leaders?
The bleeding disorders community has experienced significant challenges from little to no treatment options, the tragedy that befell the community due to contaminated blood products and for some patients in Europe access to treatment is still a significant challenge. But out of personal difficulties, systemic challenges and medical tragedies rose powerful, passionate and educated leaders who have fought to ensure improvements in access for patients to the safest and most efficacious products available. With the increasing availability of treatment products for people with bleeding disorders, we ask the question will we continue to have commitment from future leaders when the path to access seems to be improving for some?

Debate 2: Ageing & Haemophilia: Is specific advocacy required?
For the first time in our community, and thanks to improvements in treatment, patients with haemophilia, will live long enough to experience the problems associated with ageing. These patients will now face problems associated with having a chronic bleeding disorder such as difficulties with joints, poor venous access, comorbidities and adherence, alongside the complexities of ageing at a time when the management of ageing and haemophilia is relatively unknown. For ageing patients with haemophilia, working together with their haematologists, geriatricians and the wider multidisciplinary care team will be essential in ensuring good health into the future. As a patient community we ask - is our community responsible for specific and targeted education for these patients and their care-givers, and even the broader community on ageing with haemophilia?

The objective of these debates is to stimulate a real and thought-provoking conversation on current hot topics in our community from different perspectives and fields of expertise. Will the youth representatives present brilliant new ideas? Or, will the esteemed figures in the haemophilia community prove to be young at heart and have a more refreshing approach? Join us on Friday at 19.00 to find out!

Follow and join the debate on Twitter by using #EHCYouthDebate!

The EHC would like to thank Sobi for their support in providing training to our Youth Debate participants.

See the debate programme on page 12.
MESSAGE FROM THE PRESIDENT OF THE EUROPEAN HAEMOPHILIA CONSORTIUM

Dear Delegates and Colleagues,

On behalf of the European Haemophilia Consortium (EHC), you are all very welcome to our 2019 Conference, which we’re pleased to co-host with our North Macedonian National Member Organisation in the beautiful and historic city of Skopje!

Thanks to the hard work of our Programme Committee, the latest and most relevant updates, discussions on a quickly-moving therapeutic landscape, patient insights and perspectives, and (hopefully) much debate await you over this weekend - we hope you will enjoy and get the most out of it!

Of course no conference programme is complete without the meaningful margins - those interesting spaces outside the sessions!

Here, too, plans have been made for you!

It starts Friday evening, when we invite you to our traditional Youth vs Established Leaders debate - and continues after dinner with our movie night, featuring the latest in EHC and NMO storytelling!

There is also the home-away-from-home EHC stand, where our staff and volunteers have numerous educational and interactive activities planned for you.

And don’t be shy about stopping at the new EHC dental booth, where volunteer experts are on-hand to answer your questions, share techniques and help support your painless dental hygiene.

When all is said and done, I hope you will return home more knowledgeable, connected and inspired than you arrived - and take with you my gratitude for our collaborations and friendship over these past eight years that I served as your EHC President.

Sincerely yours,

Brian O’Mahony
President of the European Haemophilia Consortium

MESSAGE FROM THE BLEEDING DISORDERS SOCIETY OF NORTH MACEDONIA

Greetings!

On the behalf of the Bleeding Disorders Society of North Macedonia – HEMOLOG, I would like to take the opportunity to welcome you all to Skopje, North Macedonia.

We are delighted to host the 32nd European Haemophilia Consortium Conference as one of the biggest events dedicated to bleeding disorders in Europe in our small country. We support and applaud all doctors, organisations and industry that strive to create a better life for those affected by bleeding disorders and their families.

Unconditional sharing of knowledge and experiences will only make us stronger as a community.

Together we can do a lot; we can move mountains and relieve the burden from those in need.

While you are here, please take time to enjoy the exquisite mix of traditions and cultures in our extraordinary country.

With my very best wishes for an enjoyable and successful conference.

Most sincerely yours,

Cvetanka Nakjeska
President, Bleeding Disorders Society - HEMOLOG
COMMITTEES

CONFERENCE ORGANISERS
» European Haemophilia Consortium
» NMO of North Macedonia for Bleeding Disorders – Hemolog

CONFERENCE ORGANISING COMMITTEE
» Brian O’Mahony
» Minette van der Ven
» Amanda Bok

EHC STEERING COMMITTEE
» Brian O’Mahony  President
» Minette van der Ven  Vice-President Finance
» Miguel Crato
» Dr Radoslaw Kaczmarek
» Michael van der Linde
» Olivia Romero-Lux
» Thomas Sannié
» Naja Skouw-Rasmussen
» Amanda Bok  CEO, ex-officio
» Alain Weill  ex-officio

SCIENTIFIC COMMITTEE
» Prof Flora Peyvandi
» Prof Angelika Batorova
» Prof Michael Makris
» Prof Johannes Oldenburg
» Brian O’Mahony
» Dr Radoslaw Kaczmarek

INVITED SPEAKERS & CHAIRS
» Bojan Chunde  North Macedonia
» Miguel Crato  Portugal
» Dr Roseline d’Oiron  France
» Prof Philippe de Moerloose  Switzerland
» Dr Violeta Dejanova-Ilievska  North Macedonia
» Dr Daniel Hart  United Kingdom
» Dr Radoslaw Kaczmarek  Poland
» Prof Mike Laffan  United Kingdom
» Cvetanka Nakeska  North Macedonia
» Dr Beatrice Nolan  Ireland
» Declan Noone  Ireland
» Brian O’Mahony  Ireland
» Prof Johannes Oldenburg  Ireland
» Prof Flora Peyvandi  Ireland
» Dr Glenn Pierce  Germany
» Olivia Romero-Lux  France

REGISTRATION
The Registration Desk will be open during these times:
Thursday 3 October  16.00 - 20.00  Hotel Foyer
Friday 4 October  07.30 - 19.00  Ballroom Foyer
Saturday 5 October  08.00 - 19.00  Ballroom Foyer
Sunday 6 October  08.00 - 13.00  Ballroom Foyer

Delegate registration fee includes:
» Access to all sessions of the scientific programme
» Access to the exhibition
» Buffet Supper on Thursday 3 October
» Welcome Reception and Buffet Supper on Friday 4 October
» Morning and afternoon refreshments during official breaks
» Lunch on Friday, Saturday, and a light lunch on Sunday

CONFERENCE SECRETARIAT
EHC 2019 Conference
Conference Organisers
20C The Courtyard
Castle Street, Dalkey, Co. Dublin, Ireland
T: +353-1- 2859033
E: info@conferenceorganisers.ie
www.conferenceorganisers.ie
www.ehc.eu
Putting hemophilia patients first
yesterday, today, tomorrow

At Bayer, we’re all about helping people with hemophilia to break boundaries, thrive and achieve their full potential.

We’ve been doing this for over 30 years and are proud to work with patients, caregivers and treaters to help create a strong community dedicated to reaching these goals.

But we never stop.

Our portfolio of innovative recombinant FVIII therapies has the potential to set new standards of care. And, our evolving patient support programs and tireless research into gene therapy and bleeding disorders, is helping redefine what it means to live with hemophilia.

Visit the Bayer booth and attend the Bayer symposium on Sunday 10.30 – 12.00.
Learn differently.
Engage differently.
HaemDifferently.

Visit HaemDifferently.eu to learn about the science behind ongoing research in gene therapy.
Novo Nordisk is committed to driving change in haemophilia. Our key contribution is to discover and develop effective and safe medicines for people with haemophilia and other rare bleeding disorders. But we know that to truly change haemophilia, we need to do more than supply the right medicines. That is why we work with our global partners like European Haemophilia Consortium (EHC) to advocate for and create better access to diagnosis and multidisciplinary care. Changing Haemophilia® is our commitment to address the unmet needs in haemophilia.

Learn more at novonordisk.com/changinghaemophilia
Invitation
Roche-sponsored Satellite Symposium at EHC 2019

Evolving community perspectives and priorities:
embracing opportunities and addressing challenges related to novel therapies

Saturday 5 October, 2019
16.30–17.45
Ballroom 1, Marriott Skopje, North Macedonia
ReDefine aims to inspire. To **SPARK CONVERSATION**. To encourage and **MOTIVATE** people living with haemophilia to redefine their goals and aspirations, by telling it how it **REALLY IS**.

Throughout the year, we have been working with people living with haemophilia to understand how their lives are affected. The community have already shared their thoughts and feelings on the realities of life with haemophilia by creating memes for our [#MEMEOPHILIA](#MEMEOPHILIA) gallery.

**SCAN HERE TO EXPLORE**

the ReDefine website

**AND CREATE YOUR MEME**
REACH NEW HEIGHTS TOGETHER
Takeda is committed to improving the lives of people living with rare bleeding disorders, as reflected in our belief that:

But, beyond delivering medicines and therapy, we are also passionate about providing support services to engage and unite patients across the global community.

That’s why we are incredibly proud to partner with the Virgin Pulse Global Challenge* to deliver a well-being program that is focused on the needs of patients, and aims to help build healthy habits that last a lifetime. Groups of six patients, with healthcare professionals as team captains, will embark on a 100-day journey to discover tips for staying active, eating healthily, and how to refresh and refocus the body.

Come along to the Takeda booth to find out more about the Virgin Pulse Global Challenge and convert your kinetic energy into electricity to power our ‘Every Bleed Matters’ sign!

*Virgin receives payments from Takeda to fund healthcare professionals and patients to take part in the Global Challenge.
FRIDAY 4 OCTOBER 2019

07.30-19.00 Exhibition and Registration & Hospitality Desk
08.00-09.30 General Assembly (NMOs only)
09.30-10.00 Tea/Coffee – Exhibition Area – iPad raffle
10.00-12.00 General Assembly (NMOs only)
12.00-13.00 Buffet Lunch
13.00-13.45 Opening
Chair: Brian O’Mahony
13.00-13.15 Haemophilia care in North Macedonia, a clinician overview
Dr Violeta Dejanova-Ilievska
13.15-13.30 Life with haemophilia in North Macedonia, a patient perspective
Bojan Chunde
13.30-13.45 30 years of the EHC
Brian O’Mahony
13.45-15.00 Overview of new treatments in haemophilia patients with and without inhibitors
Co-Chairs: Dan Hart & Thomas Sannié
13.45-14.15 EHL: experiences with Fc-fusion, albumin-fusion and PEG products in haemophilia A and B in Europe
Prof Johannes Oldenburg
14.15-14.45 How prophylaxis is changing in haemophilia
Dr Beatrice Nolan
14.45-15.00 Discussion
15.00-16.15 Industry symposium 1 - Novo Nordisk
16.15-16.45 Tea/Coffee – Exhibition Area
16.45-18.00 Industry symposium 2 - Sobi
18.00-18.45 Reception and Tapas
18.45-19.00 Conference Opening and Welcome
Brief welcome by Maria Nakeska, Hemolog and Brian O’Mahony, President, EHC
19.00-20.00 Youth Debate
20.00-22.30 Buffet Supper

Film Screenings: Living with hepatitis C and haemophilia in Europe” (EHC, 2019), “Women and Bleeding Disorders: Untold Stories” (EHC, 2019) and “Jump above your limits!” (Lithuanian Haemophilia Society, 2019)

SATURDAY 5 OCTOBER 2019

08.00-19.00 Exhibition and Registration & Hospitality Desk
08.30-09.45 Industry Symposium 3 - Sanofi
09.45-10.15 Tea/Coffee – Exhibition Area
10.15-11.45 Quality of life & patient experience on first available non-replacement therapy
Co-Chairs: Prof Flora Peyvandi & Miguel Crato
10.15-10.35 Patient experience on Emicizumab
Dr Radoslaw Kaczmarek
10.35-11.05 Clinical management with Emicizumab
Dr Dan Hart
11.05-11.25 How safety of novel anti-hemophilic drugs should be approached. Known and unknown adverse effects
Prof Flora Peyvandi
## CONFERENCE PROGRAMME  BALLROOM 1

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<td>Discussion</td>
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<td>11.45-13.00</td>
<td>Industry Symposium 4 - BioMarin</td>
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<td>13.00-14.00</td>
<td>Buffet Lunch – Exhibition Area</td>
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<td>14.00-16.00</td>
<td>Scientific updates: Novel therapies in other bleeding disorders</td>
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<td>Co-Chairs: Olivia Romero-Lux &amp; Prof Flora Peyvandi</td>
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<td>14.00-14.30</td>
<td>Prophylaxis in RBDs: What are RBD and when is prophylaxis needed</td>
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<td>Dr Roseline d’Oiron</td>
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<td>14.30-15.00</td>
<td>Prophylaxis in VWD: Focus on diagnosis and treatment</td>
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<td>Prof Mike Laffan</td>
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<td>15.00-15.30</td>
<td>Management of women with fibrinogen deficiency</td>
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<td>Prof Philippe De Moerloose</td>
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<td>15.30-15.45</td>
<td>Economic considerations in RBDs</td>
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<td>Declan Noone</td>
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<td>15.45-16.00</td>
<td>Discussion</td>
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### SUNDAY 6 OCTOBER 2019

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<td>Exhibition and Registration &amp; Hospitality Desk</td>
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<td>08.30-10.15</td>
<td>Scientific updates: Gene therapy</td>
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<td>Co-Chairs: Brian O’Mahony and Dr Glenn Pierce</td>
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<td>08.30-09.00</td>
<td>Overview of the latest developments in gene therapy clinical trials</td>
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<td>Prof Flora Peyvandi</td>
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<td>09.00-09.30</td>
<td>Regulatory perspectives on gene therapy</td>
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<td>Dr Glenn Pierce</td>
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<td>09.30-10.00</td>
<td>Patient perspectives on gene therapy</td>
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<td>Dr Radoslaw Kaczmarek</td>
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<td>10.00-10.15</td>
<td>Discussion</td>
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<td>Industry Symposium 6 - Bayer</td>
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<td>12.00-13.45</td>
<td>Creating a mind-shift: Preparing and shaping the future</td>
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<td>Co-Chairs: Dr Radoslaw Kaczmarek &amp; Prof Johannes Oldenburg</td>
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<td>12.00-12.30</td>
<td>Haemophilia care in Europe and future measurements</td>
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<td>Declan Noone</td>
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<td>12.30-13.00</td>
<td>Ensuring sustainability: How to improve treatments without increasing</td>
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<td>Prof Johannes Oldenburg</td>
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<td>13.00-13.30</td>
<td>Future role of the haemophilia societies in the era of novel products</td>
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<td>Two perspectives</td>
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<td>Brian O’Mahony and Thomas Sannié</td>
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<td>13.30-13.45</td>
<td>Discussion</td>
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<td>13.45-14.00</td>
<td>Closing remarks followed by light lunch</td>
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<td>Brian O’Mahony, President, EHC</td>
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<td>Maria Nakeska, Hemolog</td>
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**32nd EHC Conference | 2019**
SYMPOSIA PROGRAMMES BALLROOM 1

FRIDAY 4 OCTOBER 2019

15.00-16.15 DONATED TO THE EHC BY NOVO NORDISK
ACCESS TO TREATMENT AND CARE FOR WOMEN WITH BLEEDING DISORDERS
Moderated by: Yannick Colle and Tatjana Markovic

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| 15.00 – 15.05 | Introduction to the workshop

  Moderators

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| 15.05 – 15.15 | Highlights from the WBD Conference

  Laura Savini

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| 15.15 – 15.35 | Access to multidisciplinary treatment

  Debra Pollard

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| 15.35 – 15.55 | Management of menorrhagia in rare factor deficiency and platelet disorders

  Dr Roseline d’Oiron

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| 15.55 - 16.10 | Panel discussion and Q&A

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| 16.10 – 16.15 | Conclusions

The EHC would like to thank Novo Nordisk for the unrestricted donation of this symposium

16.45-18.00 SATELLITE SYMPOSIUM HOSTED BY SOBI
UNLOCKING A WORLD OF POSSIBILITIES FOR PEOPLE WITH HAEMOPHILIA?

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| 16.45 – 16.55 | Welcome & Introduction

  Clive Smith, United Kingdom

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| 16.55 – 17.15 | Living life beyond haemophilia: Can good be better?

  Clive Smith, United Kingdom

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| 17.15 – 17.50 | Liberate life for the future: Opportunities to live well with haemophilia (panel discussion)

  Clive Smith, United Kingdom

  Andrea Buzzi, Italy

  Dr Gary Benson, United Kingdom

  Michael van der Linde, The Netherlands

  Meri Korpilahti, Finland

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| 17.50 – 17.55 | Questions and Answers

  Clive Smith, United Kingdom

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| 17.55 – 18.00 | Closing remarks

  Clive Smith, United Kingdom

19.00 - 20.00 YOUTH DEBATE PROGRAMME

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| 19.00 – 19.05 | Introduction

  Brian O’Mahony President EHC

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| 19.05 – 19.30 | Debate 1: Adversity bred leadership: Will we have commitment from future leaders?

  Christian Berner, Austria

  vs

  Marija Aloe Vera Drzmanoska, North Macedonia

  Professional Rebuttals:

  Clive Smith

  Dr Glenn Pierce

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  William Mc Keown, United Kingdom

  vs

  Xhulio Xhaferaj, Albania

  Professional Rebuttals:

  Jamie O’Hara

  Dr Radoslaw Kaczmarek

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| 19.55 – 20.00 | Closing and Discussion

  Brian O’Mahony
SYMPOSIA PROGRAMMES

SATURDAY 5 OCTOBER 2019

08.30-09.45 DONATED TO THE EHC BY SANOFI

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<td>Introduction from Sanofi</td>
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<td>08.35 – 08.45</td>
<td>Group icebreaker</td>
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<td>08.45 – 08.55</td>
<td>EHC youth strategy – the why &amp; how</td>
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<td>Amanda Bok, CEO EHC</td>
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<td>08.55 – 09.10</td>
<td>EHC Youth Fellowship Programme</td>
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<td>Fiona Brennan, EHC Community Programmes Officer</td>
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<td>09.10 – 09.35</td>
<td>Panel discussion with Youth Fellowship Programme participants, established NMO leaders and EHC staff members</td>
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<td>09.35 – 09.45</td>
<td>Questions and Discussion</td>
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The EHC would like to thank Sanofi for the unrestricted donation of this symposium.

11.45-13.00 BIOMARIN SYMPOSIUM

THINKING DIFFERENTLY IN HAEMOPHILIA: THE LANGUAGE OF GENE THERAPY

Chair: Dr Glenn Pierce, MD, PhD, Vice President, World Federation of Hemophilia (WFH)

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<td>Dr Glenn Pierce</td>
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<td>Vice President, WFH, USA</td>
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<tr>
<td>11.55 – 12.20</td>
<td>The importance of language</td>
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<td>Tamás Bereczky</td>
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<td>European Patients’ Academy, Berlin, Germany</td>
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<td>12.20 – 12.45</td>
<td>The language of gene therapy</td>
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<td>Dr Dan Hart</td>
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<td>The Royal London Hospital, London, United Kingdom</td>
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<td>12.45 – 12.55</td>
<td>Audience discussion and Q&amp;A</td>
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<td>All</td>
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<td>12.55 – 13.00</td>
<td>Summary and Closing</td>
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<td>Dr Glenn Pierce</td>
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16.30-17.45 ROCHE SYMPOSIUM

EVOLVING COMMUNITY PERSPECTIVES AND PRIORITIES: EMBRACING OPPORTUNITIES AND ADDRESSING CHALLENGES RELATED TO NOVEL THERAPIES

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<td>Amanda Bok</td>
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<td>16.35 – 17.00</td>
<td>The Israeli experience: What can we learn?</td>
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<td>Amanda Bok, Mudi Misgav, Nir Sharon, Liora Tevet and Gaby Golan</td>
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<td>17.00 – 17.25</td>
<td>Passing the torch: How do we share experience and support across the community?</td>
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<td>Amanda Bok, Mudi Misgav, Nir Sharon, Liora Tevet and Gaby Golan</td>
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<td>17.25 – 17.40</td>
<td>Audience Q&amp;A</td>
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<td>17.40 – 17.45</td>
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<td>Amanda Bok</td>
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SYMPOSIA PROGRAMMES BALLROOM 1

SUNDAY 6 OCTOBER 2019

10.45-12.00 BAYER SYMPOSIUM
MOVING FORWARD TOGETHER: THE ENDURING ROLE OF FVIII THERAPY AS STANDARD OF CARE IN HEMOPHILIA A

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Speaker(s)</th>
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<tbody>
<tr>
<td>10.45</td>
<td>Patient aspirations at the centre of FVIII therapy development: What the HemACTIVE survey is telling us</td>
<td>Gregory Le Cleir</td>
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<td>10.50</td>
<td>Clinical progression: The data behind FVIII therapy</td>
<td>Dr Maria Elisa Mancuso</td>
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<td>11.05</td>
<td>Practical progression: FVIII role in prophylaxis and beyond</td>
<td>Dr Kate Khair</td>
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<td>11.20</td>
<td>Outcomes progression: The confidence behind FVIII therapy</td>
<td>Dakota Rosenfelt</td>
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<td>11.35</td>
<td>Sharing support: Bayer’s commitment to haemophilia</td>
<td>Alex Mehuys</td>
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<td>11.50</td>
<td>Q&amp;A and Closing</td>
<td>All</td>
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SOCIAL PROGRAMME

WELCOME RECEPTION AND BUFFET DINNER MARRIOT HOTEL SKOPJE
Friday 4 October  18.00-22.30
The Welcome Reception and Buffet Dinner will take place in the Marriott Hotel in the Foyers and Ballrooms.
18.00-18.45      Reception and Tapas
18.45-19.00      Conference Opening and Welcome
Brief welcome by Maria Nakeska, Hemolog and Brian O’Mahony, President, EHC
19.00-20.00      Youth Debate
20.00-22.30      Buffet Supper
Film Screenings: Living with hepatitis C and haemophilia in Europe” (EHC, 2019), “Women and Bleeding Disorders: Untold Stories” (EHC, 2019) and “Jump above your limits!” (Lithuanian Haemophilia Society, 2019)

CONFERENCE DINNER RESTAURANT VEZILKA
Saturday 5 October  20.00-24.00
The Conference Dinner is being held in Vezilka. The coach transfers depart at 19.15 from the Marriott Hotel. There will be music and dancing after dinner.
Please bring your ticket with you to ensure admission on the coach and to the dinner.
During the coffee breaks come visit the EHC stand and hear about the highlights of our work!

Friday 4 October
16.15-16.45
Women and Bleeding Disorders
- Meet the Women and Bleeding Disorders Committee
- Learn about their activities and how you can get involved
- Find out about the second edition of the WBD Conference

Saturday 5 October
9.45-10.15
EHC Youth Strategy
- Meet the Youth Committee
- Learn more about the Youth Fellowship Programme
- Hear about our plans for 2020

16.00-16.30
European Inhibitor Network
- Meet the Inhibitor Working Group
- Leaf through our brand new Handbook for better inclusion of people with inhibitors in the life of the NMOs
- Take a photo with Inhibitox, the inhibitor superhero

Sunday 6 October
10.15-10.45
New Technologies
- Meet the volunteers behind the New Products Newsletter
- Learn how you can get informed about novel treatments
Creating a path for advancements in haemophilia gene therapy research

“It’s incredible to think what transformative advances gene therapy could bring...it has been my focus for the past two decades to solve this challenge.”

Katherine A. High, M.D., President and Head of Research and Development

“As a medical professional, I’m excited that gene therapy research may lead to potential treatments for patients with haemophilia.”

Leonard Valentino, M.D., Medical Strategy Lead, Haematology

We recognise that the path to transforming the lives of patients takes curiosity, courage and drive. The resilience of the people we serve is our inspiration to push through barriers to success. With your continued support, Spark Therapeutics is striving to challenge the inevitability of genetic disease by discovering, developing and delivering treatments in ways unimaginable – until now.
EXHIBITION

The Exhibition is taking place in the Ballroom 2 and the Ballroom Foyer in the Marriott Hotel where refreshments and lunch will be served during official conference breaks. The Exhibition is open for the duration of the conference and we encourage delegates to visit the stands.
GENERAL INFORMATION

MOBILE DATA
North Macedonia is NOT in the EU mobile phone data roaming system. You may incur substantial charges if you use your mobile phone data plan. Please contact your mobile provider to inquire about international data plans that cover North Macedonia.

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.

CERTIFICATES OF ATTENDANCE
Certificates of Attendance have been included in each registered delegate’s onsite documents.

TREATMENT ROOM
The Treatment Room is located in Meeting Room B. The treatment room will be open for the duration of the conference and will be staffed by nurses.

COFFEE BREAKS
Coffee and tea will be served, during the scheduled breaks, in Ballroom 2 and the Ballroom Foyer where the exhibition is being held.

LUNCH
Lunch will be served in Ballroom 2 and the Conference Foyer where the exhibition is being held.

BREAKFAST
For delegates staying at the Marriott Skopje Hotel, breakfast is served in the Distrikt Restaurant from 06.30-11.00 (Monday to Friday) and from 07.00-11.00 on the weekend.

CLOAKROOM
There is an unmanned cloakroom located on the second floor in the foyer area, which will be open during the conference opening hours.

INTERNET FACILITIES
Wireless Internet access is available throughout the Marriott Skopje Hotel. Select WIFI Marriott Conference [no password] to access complimentary WIFI at the conference.

INSURANCE
The EHC Organising Committee, or its agents, will not be responsible for any medical expenses, loss, theft, damages or accidents during the event. We recommend that delegates insure themselves for medical and cancellation charges.

CONFERENCE LANGUAGE
The official language of the conference is English. Simultaneous translation will be available in Russian during the conference sessions in the main meeting room, Ballroom 1, on Friday, Saturday and Sunday.

VOLUNTEERS
There are volunteers available to assist wheelchair users and delegates with mobility difficulties. The volunteers are all wearing white T-shirts with the Sanofi and EHC 2019 conference logo.

SPEAKER ROOM
An Audio Visual technician will be available in the Speaker Room - Meeting Room A - and all speakers should make contact with the technician as soon as possible after registration and no later than 3 hours before their presentation.

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 sessions.

TWITTER
Delegates are invited to tweet during the conference using the #EHC2019, #YouthDebate and follow on @EHC_haemophilia.
LOCAL INFORMATION

NEAREST TREATMENT CENTRE
St. Mother Theresa No.17, Skopje
Haemophilia Treatment Centre part of Institute for Transfusionology
Telephone: +389 75 283 435
Website: http://itm.org.mk
Normal working hours: Monday-Friday 08.00-15.00
Outside Normal Working Hours: On call Transfusionologist, Dr. Violeta Dejanova-Ilievska
Telephone: (+389) 75 283 435 / 70 739 459

AIRPORT SHUTTLE TRANSFER BUS
An EHC Conference Shuttle Transfer Bus will be available to the Marriott Hotel on Thursday 3 October and Friday 4 October. The transfers are primarily intended for delegates with mobility difficulties who take priority on available seats. EHC volunteers will be in the Arrivals Hall and will guide delegates to the bus.
Approximate departure times from Skopje International Airport to the Marriott Hotel are as follows:
Thursday 3 October: 08.00; 10.00; 12.00; 14.00; 16.00; 18.00; 20.00
Friday 4 October: 08.00; 10.00; 12.00; 14.00; 16.00; 18.00; 20.00
There will be one coach returning to Skopje International Airport at 14.00 on Sunday 6 October. This transfer is primarily intended for delegates with mobility difficulties who take priority on available seats.

AIRPORT PUBLIC TRANSPORT
There is a bus from Skopje International Airport to the city centre. The nearest bus stop to the Marriott, Solun and Ibis Hotels is the Holiday Inn and it is approximately an 8-minute walk to these hotels. The latest bus timetable is available at http://vardarexpress.com.

PUBLIC TRANSPORT
Public transportation in Skopje is by bus. There is a dense network of bus lines connecting most parts of the city and suburbs. There are two companies: JSP - “Public Transport Company” and “Sloboda prevoz”. You must use the local currency to pay on the buses.

TAXIS
Taxis are available throughout the city and can be found almost at every corner, 24 hours a day. Taxis in Skopje are relatively inexpensive. A taxi from Skopje International Airport to the Marriott Hotel Skopje will cost €20. The taxi services at Skopje International Airport are regulated by the price list, which is exhibited at the exit of the airport and in each taxi vehicle separately. The vehicles of the Airport taxi company are all a white colour and marked with a taxi sign numbered from 1 to 65.

Pay attention to the taxis’ sign and use an official taxi company where the taxis have a meter on. Payment is always in local currency, most of the taxi companies do not accept credit cards.

SHOPPING & WORKING HOURS
Government and local administration offices are generally open to the public from 08.30-15.00. Most stores are open from 09.00-18.00. For shops, opening hours are largely deregulated, but are limited to a maximum number of hours per week: shops are closed one day a week, but not necessarily on Sundays. Pubs, bars and restaurants are usually open until 00.00 or 01.00 on the weekend.

Banks are generally open from 09.00 - 16.30 Monday to Friday and some banks are open on Saturday.

CURRENCY & BANKING
National currency is the North Macedonian Denar.
Foreign currencies can be easily exchanged in banks and in a large number of private exchange offices. 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 at the entrance.

DISABILITY ACCESS
It is advisable to check with all tourist attractions prior to your visit, ensuring that they are able to meet your particular needs. Advance notice and reservations will also help ensure that you receive the best possible assistance.

SAFETY
North Macedonia is a relatively safe country with few threats to travellers’ safety.

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

TELEPHONE CALLS
Country Code: +389
Emergency Services: 112
To make international calls dial the International Access Code 00.

CLIMATE
The average temperatures in October in Skopje will be between 8.5°C and 19.0°C.
FOCUSED ON DEVELOPING SPECIALTY TREATMENTS
for debilitating diseases that are often difficult to diagnose and treat, providing hope to patients and their families.

Sanofi Genzyme is proud to support the European Haemophilia Consortium’s continued efforts to improve the lives of patients and caregivers across Europe
Support is gratefully acknowledged from the following organisations:

PLATINUM SPONSORS

Roche
sobi
Takeda

Sobi contributed to the travel grants of delegates from developing countries

GOLD SPONSORS

Biomarin
Bayer
Novo Nordisk
Sanofi
Spark Therapeutics

CSL Behring contributed to the travel grants of delegates from developing countries

SILVER SPONSORS

CSL Behring
uniQure

Sponsorship does not cover any social events
Each of us is born under different circumstances, with different dreams, skills and opportunities. What happens when you let your dreams and your drive dictate what is possible? What happens when you not only recognise your rare strength but release it? Visit liberatelif.eu and follow five people’s journeys as they explore life beyond haemophilia.

Liberate Life is a vision for people like you who are living with haemophilia. Liberate Life builds on our dedication to opening up opportunities. Liberate Life is about living life beyond haemophilia, and celebrating life without compromise.

liberatelif.eu