SHOW ME THE DATA! CHALLENGES AND OPPORTUNITIES IN DATA COLLECTION

PD-S-01

ROOM: 307
Chair: Alfonso Iorio, Canada
This workshop will be open to healthcare professionals who are involved in research and/or advocacy activities in the bleeding disorders community and have an active interest in using health data in their work. In addition to national patient organizations, the intended audience of the workshop will include professionals from hemophilia treatment centres.

08:30
Intro and overview – Alfonso Iorio, Canada

08:40
Building a strong base of evidence
- What is good quality data? – Alfonso Iorio, Canada
- What constitutes good evidence for advocacy? – Randall Curtis, U.S.A.
- Ethical and legal challenges in data collection – Margareth Ozelo, Brazil

09:10
Winning coalition: Who is involved in successful data collection?
- Role of the patient and national patient organizations – David Page, Canada
- Role of the institution – Kathelijne Fischer, the Netherlands
- Role of the Researcher – Jeff Stonebraker, U.S.A.

09:45 Break

10:00
How to use and communicate data effectively
- Presentation on the WFH Annual Global Survey – Christine Herr, Canada
- How to communicate effectively – Saeed Ul Hassan, Pakistan
- Group activity: Communicating and presenting data

10:55
Regional experiences and challenges in data collection
- Emerging Registry – Anne-Louise Cruickshank, South Africa
- Panel discussion: Success stories, challenges faced, outcomes – Mike Soucie, U.S.A.; Kathelijne Fischer, the Netherlands; David Page, Canada

11:20
Conclusion and summary – Alfonso Iorio, Canada
09:00–10:30

GENETIC COUNSELING: UNDERSTANDING THE ROLE WITH PATIENTS AND FAMILIES

PD-S-02

sponsored by Baxalta now part of Shire—non CME session

ROOM 206
Chair: Ed Kuebler, U.S.A.

09:00
Genetic counseling: What patients and families need to know – Jennifer Lemon, U.S.A.

09:20
Comparison of genetic counsellors versus other hemophilia treatment centre providers: Opportunities for collaboration in a hemophilia treatment centre – Michelle Alabek, U.S.A.

09:40
Considerations in less developed countries – Richa Mohan, India

10:00
Nurse’s perspective: The importance of genetic testing for individuals with hemophilia and their female relatives – Regina Butler, U.S.A.

09:00–12:30

MUSCLOSKELTAL PROFESSIONAL DEVELOPMENT DAY

PD-S-03

ROOM 204
Chair: Mauricio Silva, U.S.A.

09:00
Welcome and introductions of the Committee – Mauricio Silva, U.S.A.

09:20
Plenary/Keynote
  ▪ Achieving the impossible: The marathon experience – Luigi Solimeno, Italy

10:20 Meet and greet
  Note: Refreshments will be served

11:20
Ask the experts – Adolfo Llinas, Colombia; Kathy Mulder, Canada; Axel Seuser, Germany

12:00
Closing remarks – Nicholas Goddard, United Kingdom
10:45–16:00

NURSES PROFESSIONAL DEVELOPMENT DAY: IT’S A SMALL WORLD: CARING FOR PATIENTS AROUND THE WORLD

PD-S-04

-sponsored by Baxalta now part of Shire—non CME session

ROOM 206

Chair: James Munn, U.S.A.

10:45

Introduction for the day – James Munn, U.S.A.

11:00

Concordance and adherence
  - Introduction – Kate Khair, United Kingdom
  - Concordance – Deborah Gue, Canada
  - Adherence – Michelle Witkop, U.S.A.

12:00

Cultural talk: National Hemophilia Foundation – Maria Santaella, U.S.A. (Spanish presentation)

12:45 Networking lunch

Note: Box lunches will be served for participants registered for this workshop.

13:45

Evolving care for global needs
  - Prophylaxis – Ana Claudia Acerbi Vrabic, Brazil
  - WFH Humanitarian Aid Program and strategies to address issues faced by refugee and immigrant patients – Assad Haffar, Canada

14:20

WFH Global Survey results – Bonji Mbele, South Africa

14:40

Free papers: Abstract selected presentations
  - Comparing nursing strategies in Central Venous Access Device (CVAD) care: Can we reduce complications? Data of the Pednet Cohort Study – Kate Khair, United Kingdom
  - A pilot study into the experiences of hemophilia patients and caregivers in the use of indwelling Port-A-Cath devices – Collette Pigden, United Kingdom
  - Developing research skills of the hemophilia nurse: A collaborative Canadian project – Erica Crilly, Canada
  - Initial results of a collaborative nursing service aimed at improving adherence in hemophilia A patients with inhibitors to FVIII – David Stephenson, United Kingdom
  - The psychological burden of prophylaxis injection therapy on parents of children with hemophilia in Japan – Kayoko Omura, Japan

15:55

Closing remarks – Jim Munn, U.S.A.; Kate Khair, United Kingdom

16:00–17:00 Nurses “Meet and greet”

Note: WFH and NHF Working Group welcomes nurses to share refreshments at a Meet and Greet after the professional development day session. (Sponsored by WFH and NHF)
10:45–16:00

PSYCHOSOCIAL PROFESSIONAL DEVELOPMENT DAY: “LET IT GO”

PD-S-05

ROOM 205

Chair: Anne Duffy, Ireland

10:30
Registration – Silvina Grana, Argentina

10:45
Welcome and WFH Psychosocial Committee (PSC) introductions – Anne Duffy, Ireland

11:00
The importance of humour in healing and coping with chronic illness – Anne Duffy, Ireland; Ed Kuebler, U.S.A.

11:30
- WFH Psychosocial Curriculum – Fiona Robinson, Canada
- WFH PSC Psychosocial Toolkit – Susan Cutter, U.S.A.; Colleen McKay, New Zealand; Sylvia von Mackensen, Germany

12:30 Networking lunch

Note: Box lunches will be served for participants registered for this workshop.

13:15
A holistic psychosocial approach to treating patients with bleeding disorders – Sabrina Farina, Dana Francis, Laura McGinity, Joanne Fadale-Wagner (members of the NHF Social Work Working Group, United States)

14:15 Break

14:30
Sexuality through the life cycle in persons with bleeding disorders – Frederica Cassis, Brazil; Anne Duffy, Ireland

15:15
Dealing with stigma for persons with bleeding disorders – Tony Roberts, South Africa

16:00
Closing remarks and program evaluation – Susan Cutter, U.S.A.

16:15–17:00 Psychosocial “Meet and greet”

Note: WFH and NHF Working Group welcomes psychosocial workers to share refreshments at a Meet and Greet after the professional development day session.

(Sponsored by WFH and NHF)
11:45–13:15

PUBLISHING WORKSHOP: TIPS FROM THE EDITORS OF HAEMOPHILIA JOURNAL

**PD-S-06**

**ROOM 307**

Chair: *Michael Makris, United Kingdom*

**11:45**

What is happening in the world of publishing and its impact on the *Haemophilia* journal – *Sarah Tatum, United Kingdom*

**12:05**

How to write a paper and target it for the *Haemophilia* journal – *Michael Makris, United Kingdom*

**12:25**

How to review a paper and respond to the editor – *Craig Kessler, U.S.A.*

**12:45**

What are they and what to do about them: 1. Orchid ID and 2. Plagiarism – *Michael Makris, United Kingdom*

**13:05**

Questions

13:00–16:00

VWD: DIAGNOSIS AND MANAGEMENT

**PD-S-07**

*-sponsored by Baxalta now part of Shire—non CME session*

**ROOM 204**

Chair: *Flora Peyvandi, Italy*

**13:00**

Diagnosis of VWD: Introduction and overview of WFH activities – *Flora Peyvandi, Italy*

**13:10**

The role of second level tests in the diagnosis of type 2 von Willebrand disease – *Francesca Stufano, Italy*

**13:25**

Novel assays for von Willebrand Factor (VWF) functional activity – *Imre Bodo, U.S.A.*

**13:40**

Bleeding evaluation of patients affected with VWD: Which bleeding score to use? – *Augusto Federici, Italy*

**13:55**

Panel discussion
14:10 Break

14:40
Diagnosis of VWD: Strategies for the developing world – Sukesh Nair, India

15:00
Case studies and question period: Challenges in diagnosis of VWD – Steve Kitchen, United Kingdom

15:15
Dental health in patients affected with VWD – Alison Dougall, Ireland

15:30
Management of women with VWD – Andra James, U.S.A.

15:45
Panel discussion

14:30–17:00

WFH/NHF YOUTH WORKSHOP: TRANSITIONS—SHARING PERSONAL AND ORGANIZATIONAL EXPERIENCES ON KEY YOUTH ISSUES

PD-S-08

ROOM 203

Chair: Deon York

14:30
Welcome – Deon York, New Zealand

14:35
Ice breaker activity – National Youth Leadership Institute (NYLI)

14:50
From pre-diagnosis to diagnosis – Jenna Lovell, Australia

15:00
From pediatric treatment to adult treatment – Mohamed Soliman, Egypt

15:10
Learning to advocate for yourself, as a patient – Nikole Scappe, U.S.A.

15:20
From school to work – Jared Formalejo, Philippines

15:30
Putting youth in charge of their own programming – Firaoli Kumbi, Ethiopia

15:40
Succession planning for national member organizations leadership – Miguel Izquierdo
15:50
Sharing of other experiences: Open forum and question period

16:05
Presentation on National Youth Leadership Institute – Michelle Cecil and Joelle Palmatier, U.S.A.

16:30 Refreshments and socialization

13:30–17:00
RESEARCH EPIDEMIOLOGY WORKSHOP
PD-S-09
ROOM 307
Chair: David Lillicrap, Canada

13:30
Introduction to the WFH Research Program: Why do we need clinical data and what the WFH is doing to facilitate and provide support – David Lillicrap, Canada

13:40
Introduction to the WFH Clinical Research Grant Program – David Lillicrap, Canada

14:00
Planning clinical research
  ▪ The idea, importance, novelty, plausibility, and feasibility – Arijit Biswas, Germany
  ▪ The development of a research team, study design, and statistics – Samantha Gouw, the Netherlands

14:30
Planning clinical research: Reporting study results, orally and with manuscripts – Sebastien Lobet, Belgium

14:45
Questions

15:00
Models of international, practice-based data collection
  ▪ PedNet – Marijke van den Berg, the Netherlands
  ▪ Community Counts – Mike Soucie, U.S.A.
  ▪ EUHASS – Michael Makris, United Kingdom

15:45
Standardizing outcomes data collection – The Universal Case Record Form – Alok Srivastava, India

16:00
WFH Epidemiological Research Program – Glenn Pierce, U.S.A.

16:15
Panel discussion
08:45–09:15

GENERAL PLENARY

PL-M-01 – PLENARY
HALL A4
Intro: Marijke van den Berg, the Netherlands
Treatment for All: Another side of the equation
Alain Weill, France

09:30–10:00

CONCURRENT PLENARIES

+ PLM-M-01 – MEDICAL PLENARY
HALL A4
Intro: Craig Kessler, U.S.A.
Rethinking events in the hemostatic process: role of factor V and TFPI
Rodney Camire, U.S.A.

♦ PLMT-M-02 – MULTIDISCIPLINARY PLENARY
HALL B3
Intro: Thomas Sannié, France
Patient partnerships: The next step in hemophilia care
Vincent Dumez, Canada

10:00–10:45

REFRESHMENT BREAK & POSTER VIEWING

10:45–12:15

CONCURRENT SESSIONS

+ S-M-01 – MEDICAL

Extended half-life factor products
HALL A4
Chair: Ellis Neufeld, U.S.A.
- Extended half-life factor products: Results of clinical trials in pediatric studies
  – Guy Young, U.S.A.
- Extended half life FVIII and FIX in adolescent and adults – Johnny Mahlangu, South Africa
- Critique – Ellis Neufeld, U.S.A.
**S-M-02 – MULTIDISCIPLINARY**

*The real face of inhibitors: A panel discussion*

**HALL B3**

**Chair:** Kate Khair, United Kingdom
- Parent of a child with inhibitors – Kari Atkinson, U.S.A.
- Person with inhibitors – Zoe Mcgough, United Kingdom
- Person with inhibitors, successfully completed ITI – Augustus Nedzinskas, Lithuania
- Nurse from country with limited to moderate access to clotting factor concentrates – Kuixing (Jessica) Li, China

**S-M-03 – MUSCULOSKELETAL**

*The ankle*

**ROOM: 307**

**Chair:** Gianluigi Pasta, Italy
- Structural and functional analysis of the hemophilic ankle – Sebastien Lobet, Belgium
- Radiographic work up and evaluation – Andrea Doria, Canada
- Preventive measures to maintain joint health – Axel Seuser, Germany
- Staged surgical management: Timelines and techniques – Joseph Guy Asencio, France

**S-M-04 – NURSING**

*Case studies*

**ROOM: 206**

**Chair:** Marlène Beijlevelt, the Netherlands
- Type 3 von Willebrand disease – Dorcas Ramphaleng, Botswana
- Hemophilia B severe – Kam Macintosh, Canada
- Glanzmann disease – Greta Mulders, the Netherlands
- Glanzmann thrombasthenia, factor XIII deficiency, menorrhagia – Maria Tovar-Herrera, U.S.A.
- Platelet delta granule storage pool disease – Kara S. Garner, U.S.A.

**S-M-05 – PSYCHOSOCIAL**

*Communication issues and skills*

**ROOM: 204**

**Chair:** Silvina Grana, Argentina
- Family and communication issues – Diane Standish, U.S.A.
- Tools for adolescence – Silvina Grana, Argentina
- Communication with health providers – Anthony Roberts, South Africa
- Experience from a mother’s perspective – Mariana Battazza Freire, Brazil

**S-M-06 – WFH FEATURED SESSION**

*Humanitarian aid: Treatment for all is the vision of all*

**ROOM: 205**

**Chair:** Assad Haffar, Canada
- Introduction: The global need for basic hemophilia care – Assad Haffar, Canada
- WFH Cornerstone Initiative – Megan Adediran, Nigeria
- AFATH Program – Thomas Sannie, France
- The HTC experience with the WFH Humanitarian Aid Program – Kibet Shikuku, Africa
- Corrective surgeries – Ahmad Naseer, Maldives
- WFH Humanitarian Aid Program: Making lasting change a reality – Assad Haffar, Canada

12:15–14:15
LUNCH BREAK AND SATELLITE SYMPOSIA

14:15–15:45
CONCURRENT SESSIONS

+S-M-07 – MEDICAL
Innovating immune tolerance induction for hemophilia
HALL A4
Chair: Roland Herzog, U.S.A.
- Mechanisms of inhibitors – Shannon Meeks, U.S.A.
- Oral tolerance induction using transgenic plants – Roland Herzog, U.S.A.
- Tolerance induction through transplacental delivery of Fc fusion proteins – Sebastien Lacroix-Desmazes, France

+FP-M-01 – MEDICAL
Free papers: Hemophilia, clinical
ROOM 206
Chairs: Shannon Jackson, Canada, and Jan Astermark, Sweden
- Generation of IPS cell lines from Haemophilia A Patients – Heike Singer, Nicole Nuesgen, Johannes Oldenburg, Osman El-Maarri
- Macrovascular and microvascular endothelial function in adult males with hemophilia – Haowei (Linda) Sun, Ming Yang, Marinda Fung, Sammy Chan, Todd Anderson, Man-Chiu Poon, Shannon Jackson
- Non-neutralizing antibodies against factor VIII and the risk of inhibitor development in untreated and minimally treated patients with severe hemophilia A (SIPPET study) – Antonino Cannavo, Carla Valsecchi, Isabella Garagiola, Pier Mannuccio Mannucci, Frits R. Rosendaal, Flora Peyvandi
- Inhibitor neutralizing capacity of FVIII therapeutic concentrates depends on VWF: natural FVIII/VWF complex versus isolated FVIII. Study of eleven products. – Maria Isabel Bravo, Ana Maria Ortiz, Montserrat Costa, Salvador Grancha, Juan Ignacio Jorquera
- Discrepancies between the one-stage clotting assay and the chromogenic assay in haemophilia B – Kristina Kihlberg, Karin Strandberg, Rolf Ljung, Erik Berntorp, Jan Astermark
- Platelet function measured using the Multiplate (R) analyzer in pediatric patients with severe hemophilia A (SHA) – Margaret Rand, Hong Wang, Eileen McMillan-Ward, Victor Blanchette, Sara Israels
**S-M-08 – MULTIDISCIPLINARY**

*The evolution of patient-centred care*

**HALL B3**

**Chair:** Vincent Dumez, Canada

- Patient engagement in the research setting – Chinanye Anyanwu, U.S.A.
- Towards people-centred health systems: Examining novel efforts to engage the public and patients in research and health-system transformation – François-Pierre Gauvin, Canada
- The patient partner: strategies for empowering patients in the developing world – Latifa Lamhene, Algeria

**S-M-09 – MULTIDISCIPLINARY**

*Colouring outside the lines: Exploring creative techniques in managing hemophilia*

**ROOM: 205**

**Co-chairs:** Greig Blamey, Canada, and Richa Mohan, India

- Improving outcomes without factor: Orthotics and braces for bleeds and target joints – Pamela Narayan, India
- A psychosocial approach to thinking out of the box – Frederica Cassis, Brazil
- Hydrotherapy: Practical methods of exercise in water to improve fitness – Rachel Tiktinsky, Israel
- Music therapy – Tim Ringgold, U.S.A.

**FP-M-02 – MUSCULOSKELETAL**

*Free papers: Physiotherapy*

**ROOM 307**

**Chair:** Piet de Klein, the Netherlands

- Monitoring joint range of motion in adults with severe haemophilia: Evaluation of the haemophilia joint health score criteria – David Stephensen, Vishal Patel, Daniel Hart, Louise Bowles, Kim Elliot, Gillian Evans, John Pasi
- Engaging people with hemophilia through the use of point-of-care ultrasound – Sandra Squire, Shannon Jackson, Pat Camp
- Handwriting analysis in children with haemophilia: A pilot study – Gianluigi Pasta, Maria Elisa Mancuso, Filomena De Felice, Alexander Seuser, Luigi Piero Solimeno, Elena Santagostino, Axel Seuser
- Decrease in joint inflammation, swelling, and pain after a swimming protocol in an animal model of experimental-induced hemarthrosis – Fabio Souza, Fernanda Roque, Edilamar Oliveira, Gisele Picolo, Yara Cury, Clarice Tanaka, Suzana Mello
- Investigation of musculoskeletal and exercise factors with the potential to influence haemophilic ankle arthropathy development – Ann McCarthy, Ann Moore, Lucy Redhead, Stephen Classey, Sarah Houghton, Stephanie Taylor, Anna Wells, Pratima Chowdary
**S-M-10 – DENTAL**

*Ask the experts: Team approach to preventing dental problems for children and adults with hemophilia*

**ROOM 204**

**Chair:** Alison Dougall, Ireland

**Panel of experts:**
- Patient – Sanjay Chand, United Kingdom
- Dentist – Kirsten Fitzgerald, Ireland
- Doctor – Dan Hart, United Kingdom
- Patient Organization – Fiona Brennan, Ireland
- Nurse – Jim Munn, U.S.A.

**15:45–16:30**

*Refreshment break & moderated poster sessions / poster viewing*

**MP-M-01 – MEDICAL**

*Moderated posters: Rare bleeding disorders*

**EXHIBIT HALL – CUBE A**

**Chair:** Magdy El-Ekiaby, Egypt

**15:55**

Pharmacokinetic (PK) Comparison of Two Fibrinogen Concentrates in Patients with Congenital Fibrinogen Deficiency: Final analysis – **Bruce A. Schwartz**, Cecil Ross, Savita Rangarajan, Mehran Karimi, Sigurd Knaub, Flora Peyvandi

**16:05**

Recombinant factor XIII is safe and effective for prophylaxis in young children with congenital FXIII A-subunit deficiency: Results from the Mentor™5 international phase 3 trial – **Susan Kearney**, Aida Inbal, Andrew Will, Mike Williams, May-Lill Garly, Lotte Jacobsen, Bryce A. Kerlin

**16:15**

Investigation of possible correlation between clinical and laboratory phenotype in congenital FXI deficiency: Results from a single center – **Cristina Santoro**, Francesco Barone, Grazia Ferrara, Raffaele Angelo Bocchichio, Maria Patrizia Bicocchi, Maura Acquila, Erminia Baldacci, Francesca Paolini, Marta Chisini, Maria Gabriella Mazzucconi

**MP-M-02 – MEDICAL**

*Moderated posters: Genetics / Hemostasis tests*

**EXHIBIT HALL – CUBE B**

**Chair:** Steve Kitchen, United Kingdom

**15:55**

Next-Generation DNA sequencing for haemostatic and platelet disorders – **Anne Goodeve**, Laura Crookes, Nikolas Niksic, Nicholas Beauchamp

**16:05**

Preliminary Results of a Phase 1/2 Trial of SPK-9001, a Hyperactive FIX Variant Delivered by a Novel Capsid, Demonstrate Safety and Efficacy at the Lowest Dose Cohort – **Lindsey George**, Spencer Sullivan, Alvin Luk, Xavier Anguela, Katherine High
16:15
Heat-treated Bethesda assay in the monitoring of acquired haemophilia A – *Annette Bowyer*, Fiona Shepherd, Paul Titchard, Anna Lowe, Barbara Sampson, Paula Brown, Kerensa Leeson, Steve Kitchen, Mike Makris

**MP-M-03 – MULTIDISCIPLINARY**

**Moderated posters: Varia**

**EXHIBIT HALL – CUBE C**

**Chair:** Mauricio Silva, U.S.A.

- Expanding the knowledge base: Collaboration between Saskatoon and Vancouver bleeding disorder teams – *Claude Bartholomew*, Jennifer King, Shannon Jackson, Joann Nilson, Linda Sun, Sandra Squire, Kami McIntosh, Deb Gue
- Afibrinogenemia: haemorrhagic and/or thrombotic disease? – *Claudia Djambas Khayat*, Georges Khayat, Bejjani Naim, Georges Tabet, Philippe De Moerloose, Alessandro Casini
- Total Ankle Replacement (TAR) in haemophilic arthropathy of the ankle – *Sanghoon Lee*, Myungchul Yoo, Jaehoon Lee, Bio Jung

**MP-M-04 – MULTIDISCIPLINARY**

**Moderated posters: Quality of life**

**EXHIBIT HALL – CUBE D**

**Chair:** Randall Curtis, U.S.A.

- Comparison of health utilities in persons with hemophilia B – *Joanne Wu*, Mimi Lou, Femida Gwadry-Sridhar, Joan Wasserman, Brenda Riske, Judith Baker, Jeffrey Hord, Barbara Konkle, Jason Doctor, Michael Nichol
- Subjective physical functioning and health-related quality of life in children with severe haemophilia in the UK – Results of the SO-FIT Study – *Kate Khair*, Mike Holland, Anja Griffioen, Melanie Bladen, Paul McLaughlin, Sylvia von-Mackensen
- The Patient Reported Outcomes Burdens and Experiences (PROBE) Study Phase 1 methodology and feasibility results – *Mark Skinner*, Randall Curtis, Neil Frick, Alfonso Iorio, Michael Nichol, Declan Noone, Brian O’Mahony, David Page, Jeff Stonebraker
16:30–18:00

CONCURRENT SESSIONS

+S-M-11 – MEDICAL
Alternative therapies in management of inhibitors (approach of hemostasis)
HALL A4
Chair: Midori Shima, Japan
- Mechanisms of tolerance/ITI – David Lillicrap, Canada
- Porcine VIII – Rebecca Kruse-Jarres, U.S.A.
- AROSENIUS LECTURE: New data on inhibitors – Midori Shima, Japan

+S-M-12 – MULTIDISCIPLINARY
Managing patient expectation of new extended “half-life” (EHL) products
Hall B3
Chair: David Page, Canada
- Use and results of extended “half-life” (EHL): HTC perspective – Jen Maahs, U.S.A.
- Developing country perspective on humanitarian product use – Jeannie Ong, Philippines
- Extended half-life factor concentrates: A patient’s perspective – David Page, Canada
- What’s coming down the pipeline? – Pratima Chowdary, United Kingdom

+S-M-13 – MULTIDISCIPLINARY
The power and challenges of global advocacy campaigns
ROOM 205
CHAIR: Deon York, New Zealand
- A successful campaign to convince the Ministry of Health to cooperate with WFH in the GAP Second Decade Program – Latifa Lamhene, Algeria
- Advocacy tools and processes – Miguel Izquierdo, Mexico
- Alternative solutions and channels – Yuri Zhulev, Russia
- Taking a local issue to a global stage: considerations and potential dangers – Carlos Safadi, Argentina

+S-M-14 – MUSCULOSKELETAL
Surgical infections & joint replacement surgery
ROOM 307
Chair: Nicholas Goddard, United Kingdom
- Risk factors leading to infection in hemophilic patients undergoing arthroplasty – Elena Santagostino, Italy
- Thinking about arthroplasty? Take care of the teeth first! – Alison Dougall, Ireland
- Coatings and other strategies to reduce infection risk – Nick Bernthal, U.S.A.
- Surgical strategies for the treatment of the infected arthroplasty – Adolfo Llinas, Colombia
S-M-15 – LABORATORY SCIENCES
Recombinant to modified: Chromogenic or one stage assays?
ROOM 206
Chair: Elaine Gray, United Kingdom
- The impact of modified coagulation factor products on the choice of factor assays
  - Geoff Kershaw, Australia
- One-stage assay – Steve Kitchen, United Kingdom
- Chromogenic assay – Stefan Tiefenbacher, U.S.A.

S-M-16 – DENTAL
“Local” measures
ROOM 204
Chair: Graeme Ting, United Kingdom
- European perspective – Andrew Brewer, United Kingdom
- South American perspective – Miryam Parriera, Argentina
- North American perspective – Rebecca Schaffer, U.S.A.
- Asian perspective – Monthon Suwannuraks, Thailand
- Eastern Europe perspective – Branislav Bajkin, Serbia
08:45–09:15

**GENERAL PLENARY**

**PL-TU-01 – PLENARY**

**HALL A4**

*Intro:* Craig Kessler, U.S.A.

*WFH Vice-President Medical address: Preventing bleeds by treatment; new era for hemophilia*

Marijke van den Berg, the Netherlands

09:30–10:00

**CONCURRENT PLENARIES**

+ **PLM-TU-01 – MEDICAL PLENARY**

**HALL A4**

*Intro:* Marijke van den Berg, the Netherlands

*Hemophilia treatment in 2030*

Erik Berntorp, Sweden

*PLMT-TU-02 – MULTIDISCIPLINARY PLENARY*

**HALL B3**

*Intro:* Pamela Wilton, Canada

*Excessive bleeding in women: Spotlight on hemophilia carriers*

Michelle Sholzberg, Canada

10:00–10:45

**REFRESHMENT BREAK & POSTER VIEWING**

10:45–12:15

**CONCURRENT SESSIONS**

+ **S-TU-01 – MEDICAL**

*Gene Therapy*

**HALL A4**

*Chair:* David Lillicrap, Canada

- Stem cell FVIII – Chris Doering, U.S.A.
- Genome editing – Matthew Porteus, U.S.A.
- Hemophilia A gene therapy: AAV-mediated delivery of an enhanced F8 cassette to the liver produces supraphysiological levels of human FVIII in vivo – Brigit Riley, U.S.A.
S-TU-02 – MEDICAL

Comorbidities

ROOM 307

Chair: Michael Makris, United Kingdom

- Hepatitis C – Bruce Luxon, U.S.A.
- Obesity and impact on dosing – Kathelijne Peerlinck, Belgium
- New approaches on pain control: New pain medications – Michelle Witkop, U.S.A.

S-TU-03 – MULTIDISCIPLINARY

Bleeding and women: Time for a paradigm shift

HALL B3

Chair: Michelle Sholzberg, Canada

- Promotion of health and self-empowerment – Rochelle Winikoff, Canada
- Clinic maps: Exploring new directions for women with inherited bleeding disorders – Robert Sidonio, U.S.A.
- Are women with bleeding disorders managed differently than men? – Mary Brasser, New Zealand
- Are the opportunities for care and support different in women and men with inherited bleeding disorders? – Yannick Colle, France
- Are hemophilia carriers managed differently than women with VWD? – Tatjana Markovic, Serbia

S-TU-04 – MULTIDISCIPLINARY

Impact of prophylaxis for adults/children in countries with and without prophylaxis

ROOM 206

Chair: Marlène Beijlevelt, the Netherlands

- Myths and realities about prophylaxis treatment – Alok Srivastava, India
- Adherence: Different experiences around the world – Susan Cutter, U.S.A.
- Role of family: Is prophylaxis a right, a duty, a choice? – Megan Adediran, Nigeria

FP-TU-01 – DENTAL

Free papers

ROOM 204

Chair: Branislav Bajkin, Serbia

- Overview of LA in people with haemophilia followed by a multi-centre prospective study auditing the outcome of adverse events following buccal infiltration injections for patients with a range of bleeding – Alison Dougall and George Pughe
- Postoperative bleeding experience of patients with inherited bleeding disorders following periodontal therapy. A pilot study. – Aarti Shah, Lochana Nanayakkara, Claire Wilkinson, Wandai Maposa, Daniel P. Hart
- A Quality Improvement project (QUIP) regarding the prescription of haemostatic prophylaxis prior to dental treatment for patients with inherited bleeding disorders at Barts Health NHS Trust – Aarti Shah, Lochana Nanayakkara, Ibtiilhaad Hussain, Wanda Maposa, Daniel P. Hart
- A case-control study of the symptom gingival bleeding of patients with type 2 and 3 von Willebrand disease – Lisa Weickert
- Educational level and its relationship with periodontal health status in patients with hemophilia in Tabasco, Mexico – Laura Beatriz Isidro Olan and Marco Rueda

S-TU-05 – WFH FEATURED SESSION
Leading global surveillance and collaboration: The WFH’s role in ensuring safety and supply of treatment products
ROOM 205
Chair: Mark Skinner, USA
- Blood safety and donor deferrals: the history and ongoing risk evaluation – David Page, Canada
- Ensuring adequate supply and access to treatment: orphan drugs, paid plasma, and the EML – Brian O’Mahony, Ireland
- Regulatory processes and product information – Mark Brooker, Spain
- The challenge of evidence generation – Glenn Pierce, U.S.A.

12:15–14:15
LUNCH BREAK AND SATELLITE SYMPOSIA

14:15–15:45
CONCURRENT SESSIONS

S-TU-06 – MEDICAL
Making a choice: How to determine the optimal choice to treat pups
HALL A4
Chair: Keith Hoots, U.S.A.
- Introduction and overview – Cedric Hermans, Belgium
- Current data of plasma products: Safety versus immunogenicity – Alok Srivastava, India
- Current data of recombinant products: Safety versus immunogenicity – Steve Pipe, U.S.A.
- Parent of a child who had to make a choice – Julie Malan, South Africa
- Panel discussion

S-TU-07 – MEDICAL
Health technology assessment
ROOM 206
Chair: Mark Skinner, U.S.A.
- European perspective – Chris Henshall, United Kingdom
- American perspective – Cliff Goodman, U.S.A.
FP-TU-02 – MEDICAL

Free papers: Genetics of bleeding disorders
ROOM 203

Chairs: Flora Peyvandi, Italy, and Manuel Carcao, Canada

- The Factor VIII to Von Willebrand Factor Antigen (FVIII/VWF:Ag) Ratio could be Helpful in Identifying Carriers of Hemophilia A – Manuel D. Carcao, Veerle Labarque, Vanitha Perinparajah, Vanessa Bouskill, Ann Marie Stain, Cindy Wakefield, Cecilia Manuel, Victor Blanchette
- The Development of a Total Management System of Carrier Diagnosis with Gene Analysis for Hemophilia in Japan – Keiko Shinozawa
- Minimal Residual FXIII Coagulant Activity to Prevent Spontaneous Major Bleeding, On Behalf of the PRO-RBDD Group – Flora Peyvandi, Roberta Palla, Marzia Menegatti, Paolo Bucciarelli, Marco Boscarno, Laszlo Muszbek
- Exome Sequencing as A First Tier Genetic Test for Hemostatic Diseases – Waander L. van Heerde, Annet Simons, Sandy Krouwel, Selene Schoormans, Marten Nijziel
- Longitudinal Modified Hemophilia Joint Health Scores (MJHJS) Outcomes with Recombinant Factor VIII Fc Fusion Protein (RFVIIIFc) Prophylaxis in Subjects with Severe Hemophilia A – Johannes Oldenburg, Roshni Kulkarni, Alok Srivastava, Johnny Mahlangu, Stefan Lethagen, Elisa Tsao, Nisha Jain
- Genotypical Classification of Patients with Von Willebrand Disease – Waander L. van Heerde, Annet Simons, Sandy Krauwel, Selene Schoormans, Britta Laros, Paul Brons, Marten Nijziel

S-TU-08 – MULTIDISCIPLINARY

Monitoring progress through data
HALL B3

Chair: Andrew Brewer, United Kingdom

- Where to begin – Adriana Linares, Colombia
- Monitoring progress – Nigel Key, U.S.A.
- How to use the data collected – Margareth Ozelo, Brazil
- Using data to advocate for better care – TBD

S-TU-09 – MULTIDISCIPLINARY

I will take my bleeding disorder rare
ROOM 202

Chair: James Munn, U.S.A.

- Rare bleeding disorders: What is rare? How is that perceived? What are the treatment options? – Amy Shapiro, U.S.A.
- Psychosocial issues – Richa Mohan, India
- Patient perspectives – Dilli Adhikari (Factor X), Nepal; Evelyn Grimberg (Glanzmans), the Netherlands

S-TU-10 – MUSCULOSKELETAL

Re-examining the co-infection patient
ROOM 307

Chair: Greig Blamey, Canada

- Impact of new therapies on HCV and HIV – Craig Kessler, U.S.A.
- Implications of new therapies and MSK status – Paul McLaughlin, United Kingdom
The co-infected patient: What surgical issues should we expect? – Stewart Dix-Peek, South Africa

**S-TU-11 – LABORATORY SCIENCES**

*Maintaining quality in the coagulation laboratory*

**ROOM 204**

**Chair:** Steve Kitchen, United Kingdom

- Quality issues in FVIII inhibitor testing – Silmara Montalvao, Brazil
- Analyticals that help overcome pre-analyticals – Dorothy Adcock-Funk, U.S.A.
- Quality assessment of a hemostasis laboratory: Instituting and its impact – Sukesh Nair, India

**15:45–16:30**

**REFRESHMENT BREAK & MODERATED POSTER SESSIONS/POSTER VIEWING**

**+ MP-TU-01 – MEDICAL**

*Moderated posters: Hemophilia, clinical*

**EXHIBIT HALL – CUBE A**

**Chair:** Jerzy Windyga, Poland

- PROTECT VIII Kids trial results: BAY 94-9027 safety and efficacy in previously treated children with severe hemophilia A – Elena Santagostino, Kapil Saxena, Gili Kenet, Kathelijn Fischer, Tina Biss, Susan Radke, Lisa A. Michaels
- Is there a difference in inhibitor incidence with recombinant products? A meta-analysis of 2000 previously untreated patients – Alessandro Gringeri, Lorenzo Mantovani, Matteo Rota, Paolo A. Cortesi, Katharina Steinitz-Trost, Armin Reininger
- Individual baseline thrombin generation and bleeding rate during personalized prophylaxis with Nuwiq in previously treated patients with severe haemophilia A – Yesim Dargaud, Robert Klamroth, Luminita Rusen, Jerzy Windyga, Johann Bichler, Sigurd Knaub, Claude Negrier

**+ MP-TU-02 – MEDICAL**

*Moderated posters: Varia*

**EXHIBIT HALL – CUBE B**

**Chair:** Nichan Zourikan, Canada

- Transition to Fc-fusion recombinant factor IX using a pediatric PK based protocol: Real life individualized prophylaxis – Kimberly Jacobson, Susan Kearney, Jennifer Lissick, Stephanie Fritch-Lila
- The Star Excursion Balance test as a measure of lower limb function in people with Severe Haemophilia – Fionnuala Sayers, Judith Cochrane, Gary Benson
**MP-TU-03 – MULTIDISCIPLINARY**  
*Moderated posters: Varia*  
**EXHIBIT HALL – CUBE C**  
Chair: Michelle Witkop, U.S.A.

- Comprehensive care delivery for bleeding/blood disorders through telemedicine (TM) with a variety of providers at multiple delivery sites – Roshni Kulkarni, Aghiad Chamdin, Laura Carlson, Rebecca Malouin, Marcia Bird, Colleen Vallad-Hix, Michelle Witkop, Ajovi Scott-Emuakpor, Renuka Gera, Steven Gualdoni
- Validation of the Colorado Adult Joint Assessment Scale in adult patients with severe hemophilia A – Sharon Funk, Dale Walker, Sylvia Engelen, Katy Benjamin, Olga Moshkovich, Brittany Gentile, Nikki Church, Marilyn J. Manco-Johnson
- Effect of moderate intensity exercise on hemostatic capacity in adults with hemophilia A and B: Pilot study – Michelle Sholzberg, Georgina Floros, Jane E Schneiderman, Walter Kahr, Margaret Rand, Fred Pluthero, Taneya Hossain, Syed Mahamad, Jerry Teitel, Manuel Carcao

**MP-TU-04 – MULTIDISCIPLINARY**  
*Moderated posters: Women and bleeding disorders*  
**EXHIBIT HALL – CUBE D**  
Chair: Debra Pollard, U.K.

- Learning about women with bleeding through data – Cheryl D’Ambrosio, Nita Radakrishnan, Richa Mohan, Nabila Husseni
- Talking Red: A campaign for women with bleeding disorders – Christina Burgess and Liz Carroll
- Gynecologic conditions in post-menarchal adolescents with congenital bleeding disorders – Lakshmi Srivaths, Jane Geyer, Jennifer Dietrich, Roshni Kulkarni, Vanessa Byams, Qing Zhang, Anra James, Peter Kouides

**CONCURRENT SESSIONS**

**+ S-TU-12 – MEDICAL**

*Genomic approaches to bleeding disorders*  
**HALL A4**  
Chair: Andrew Mumford, U.K.

- Next-generation sequencing – Johannes Oldenburg, Germany
- Alternatives in genotyping and platelets – Catherine Hayward, Canada
- Rare bleeding disorders – Flora Peyvandi, Italy

**+ S-TU-13 – MULTIDISCIPLINARY**

*Outreach for diagnosis – Reaching the community*  
**ROOM 205**  
Chair: Roshni Kulkarni, U.S.A.

- Importance of outreach – Roshni Kulkarni, U.S.A.
- Methods of outreach – Marija Nakjeska, Macedonia
- Going rural and meeting the community – Mai Nguyen Thi, Vietnam
- Beginning with hemophilia and then going beyond – Pamela Wilton, Canada
**FP-TU-03 – MULTIDISCIPLINARY**

**Free papers**

**ROOM 203**

**Chair:** Pamela Wilton, Canada

- A risk based decision making framework – Stakeholder Consultation Essential to Appropriate Minimization of Blood Safety Risk – **Mark Skinner**, Alyson Svenson, Peter McDonald, Campbell Richards
- Vocational experiences of Canadian men with hemophilia – **Neale Smith**, Shannon Jackson, Shannon Lane, Jennifer King, Linda Waterhouse, Claude Bartholomew
- Perceived well-being in hemophilia: Emotional, social, and psychological dimensions – **Luca Negri**, Andrea Buzzì, Anna Brigida Aru, Antonio Cannavò, Angiola Rocino, Cristina Santoro, Gianluca Sottilotta, Paola Giordano, Rosamaria Mura, Flora Peyvandi, Antonella Delle Fave
- Innovative public private outreach initiative utilizing local health workers for bringing care to undiagnosed untreated hemophiliacs in remote rural districts of a state in India – **Ravi Kaushik**, Sandeep Ahuja, Ayesha Chaudhary, Nishant Singh
- Prophylaxis clinic: a novel environment outside of standard hemophilia clinic for patient-designed prophylaxis – **Deborah Gue**, Haowei Sun, Sandra Squire, Shannon Jackson

**FP-TU-04 – MUSCULOSKELETAL**

**Free papers: Orthopedic issues**

**ROOM 307**

**Chair:** Michael Heim, Israel

- Multicentric and international study evaluating clinical and subclinical venous thrombosis in patients with haemophilia undergoing major orthopaedic surgery – **Cedric Hermans**, Catherine Lambert, Vincenzo Gatteri, Walter Passeri, Pål André Holme, Marco Martinelli
- Pro-angiogenic markers in experimental hemophilic arthropathy: Insight into the angiogenesis mechanism – **Narine Hakobyan**, Xiangqian Song, Candace Enockson, Wen-Rong Lie, John O’Brian, Lin Cong
- Are clinical symptoms and impaired functional ability related to early ankle joint synovial, cartilage, and bone changes in children and young adults with haemophilia? – **David Stephensen**, Stephen Classey, Vish Patel, Stephanie Taylor, Hannah Harbidge, Anna Wells
- Chronic synovitis treated with platelet-rich plasma in patients with haemophilia – **Horacio Caviglia**, Maria Landro, Carla Daffunchio, Ana Laura Douglas Price, Noemi Moretti, Guillermo Cambiaggi, Pablo Salgado, Gustavo Galatro, Daniela Neme
S-TU-14 – NURSING

Nursing management/implications: Women, obstetrics, and delivery
ROOM 206

Chair: Robyn Shoemaker, Australia
- Managing heavy menstrual bleeding – Debra Pollard, United Kingdom
- Managing pregnancy in afibrinogenemia – Marlène Beijlevelt, the Netherlands
- Education of patients with “shemophilia”: Genetics, management, delivery, and IVF
  – Sonia Saragosa, Brazil
- Post-partum acquired hemophilia – Susan Hook, United Kingdom

S-TU-15 – PSYCHOSOCIAL

Mental health: Managing a chronic illness
ROOM 204

Chair: Edward Kuebler, U.S.A.
- Patient’s resources in the therapeutic education – Thomas Sannie, France
- Managing a chronic illness – Ed Kuebler, USA
- Experience from a patient perspective – Shanmuganathan N. Narayanan, Malaysia
- Mindfulness: The science behind the patient experience – Ira van der Steenstraten, the Netherlands
CONGRESS SESSIONS

08:45–09:15

GENERAL PLENARY

PL-W-01 – PLENARY
HALL A4
Intro: Mark Skinner, U.S.A.
Managing the risk of human spaceflight: Lesson from 50 years of NASA human spaceflight
Michael Lutomski, U.S.A.

09:30–10:00

CONCURRENT PLENARIES

PLM-W-02 – MEDICAL PLENARY
HALL A4
Intro: Michael Makris, United Kingdom
Genomics of platelet disorders
Andrew Mumford, United Kingdom

PLMT-W-02 – MULTIDISCIPLINARY PLENARY
HALL B3
Intro: James Munn, U.S.A.
Empowerment through self-care
Patrick James Lynch, U.S.A.

10:00–10:45

REFRESHMENT BREAK AND POSTER VIEWING

10:45–12:15

CONCURRENT SESSIONS

S-W-01 – MEDICAL
Rare and ultra-rare bleeding disorders
HALL A4
Chair: Philippe de Moerloose, Switzerland
- FXIII – Diane Nugent, U.S.A.
- FVII – Jean-Francois Schved, France
- Fibrinogen – Philippe de Moerloose, Switzerland

FP-W-01 – MEDICAL
Free papers: Clotting factors concentrates
ROOM 206
Chairs: Johnny Mahlangu, South Africa, and Claude Negrier, France
The pharmacokinetic profiles of intravenously and subcutaneously administered recombinant FVIIIFC-VWF-XTEN in cynomolgus monkey – **Ekta Seth Chhabra**, Nancy Moore, Douglas Drager, Sue Patarroyo-White, Ayman Ismail, Jiayun Liu, Amy Holthaus, Volker Schellenberger, John Kulman, Robert Peters

Once-weekly dosing with a long-acting glycopegylated factor IX, Nonacog Beta Pegol (N9-Gp), maintains time with high mean trough levels in previously treated adult, adolescent, and paediatric patients with severe/moderate haemophilia B – **Guy Young**, Faraizah Abdul-Karim, Manuel Carcao, Torben Colberg, Wan Hui Ong Clausen, Susan Kearney, Tadashi Matsushita, Claude Negrier, Johannes Oldenburg, Elena Santagostino, Andreas Tiede

Updated results of an ongoing long-term phase 1/2 study of Emicizumab (ACE910) in hemophilia a patients with or without inhibitors – **Keiji Nogami**, Hideji Hanabusa, Masashi Taki, Tadashi Matsushita, Tetsuji Sato, Katsuyuki Fukutake, Ryu Kasai, Koichiro Yoneyama, Hiroki Yoshida, Midori Shima

A subcutaneously administered investigational rnai therapeutic, Fitusiran (ALN-AT3), targeting antithrombin for treatment of hemophilia: interim results in patients with hemophilia A or B – **Alex Wei**, K John Pasi, Pencho Georgiev, Michael Desmond Creagh, Toshko Lissitchkov, Charles R Hay, Brigitte Brand, Pratima Chowdary, Margaret V Ragni, Benny Sorensen, Savita Ranarajan

Pharmacokinetics of BAY 94-9027, a Pegylated B-Domain: Deleted recombinant factor VIII with an extended half-life, in children, adolescents, and adults with severe hemophilia A – **Anita Shah**, Thomas Coyle, Shadan Lalezari, Benedikt Kohlstaedde, Kathelijn Fischer, Susan Radke, Lisa A. Michaels


**S-W-02 – MULTIDISCIPLINARY**

*Hemophilia: A blessing or a curse*

**HALL B3**

**Chair:** Robyn Shoemark, Australia

- Parent of a newborn – **Julie Malan**, South Africa
- Young adult with hemophilia – **Chanthearith Run**, Cambodia
- Carrier mom with son of hemophilia – **Shari Luckey**, U.S.A.
- Man who has a carrier daughter and now a grandson with hemophilia – **Lawry MacLeod**, Canada

**S-W-03 – MULTIDISCIPLINARY**

*Hepatitis C update: Complications and side-effects*

**ROOM 205**

**Chair:** Krishna Cannon, U.S.A.

- History and overview of the disease, available new treatment, and early diagnosis – **Dilip Moonka**, U.S.A.
- Success in Egypt – **Magdy El-Ekiaby**, Egypt
- Patient with a challenging, but then successful experience – **Gerard O’Reilly**, Ireland
S-W-04 – MUSCULOSKELETAL

Controversial topics in the care of patients with hemophilia

ROOM 307

Chair: Mauricio Silva, U.S.A.

- People with hemophilia undergoing joint replacement: The need for thromboprophylaxis (PRO) – Adolfo Llinas, Colombia
- People with hemophilia undergoing joint replacement: The need for thromboprophylaxis (CON) – James Luck, U.S.A.
- Large hemophilic pseudotumors: A role for conservative treatment (PRO) – Horacio Caviglia, Argentina
- Large hemophilic pseudotumors: A role for conservative treatment (CON) – Luigi Solimeno, Italy
- Compartment syndrome in people with hemophilia: A role for conservative treatment (PRO) – Michael Heim, Israel
- Compartment syndrome in people with hemophilia: A role for conservative treatment (CON) – Nicolas Goddard, United Kingdom
- Osteoporosis and hemophilia: A real clinical issue that requires treatment (PRO) – Gerry Dolan, United Kingdom
- Osteoporosis and hemophilia: A real clinical issue that requires treatment (CON) – Guinluigi Pasta, Italy

S-W-05 – LABORATORY SCIENCES

Genetic laboratory for bleeding disorders

ROOM 204

Chair: Anne Goodeve, United Kingdom

- The “My Life – Our Future” hemophilia genetic analysis project – Barbara Konkle, U.S.A.
- Pathogenic or not: Classification of genetic variants in haemostasis – Anne Goodeve, United Kingdom
- Proficient genetic laboratory at HTC and the role of training at IHTC – Eunice Sindhuvi Edison, India

12:15–14:15

LUNCH BREAK AND SATELLITE SYMPOSIA

14:15–15:45

CONCURRENT SESSIONS

S-W-06 – MEDICAL

Free Papers: Gene therapy

HALL A4

Chair: TBD

- SPK-9001 adeno-associated vector-Mediated gene therapy for hemophilia B: Sustained factor IX expression at therapeutic levels without immunosuppression – Lindsey A. George, Spencer Sullivan, Jerome Teitel, Adam Cuker, Alvin Luk. Fraser Wright, Aline Galvao, Marcus E. Carr, Xavier Anguela, Katherine A. High
Interim results of an open-label, Phase 1/2 study of BMN 270, an AAV5-FVIII gene transfer in severe Hemophilia A – John Pasi, Wing Wong Yen, Savita Rangarajan, Jonathan Wilde, David Perry, Bella Madan, Glenn Pierce, Didier Rouy

Updated results from a dose escalating study in adult patients with haemophilia B treated with AMT-060 (AAV5-hFIX) gene therapy – Wolfgang Miesbach, Marco Tangelder, Robert Klamroth, Roger Schutgens, Michiel Coppens, Peter Kampmann, Karina Meijer, Giancarlo Castaman, Federica Cattaneo, Deya Corzo, Frank Leebeek

FP-W-02 – MEDICAL

Free papers: Varia
ROOM 307

Chairs: Amy Shapiro, U.S.A., and Margareth Ozelo, Brazil

- The structural mapping of VWF propeptide missense mutations on models of d domains/tubular assembly and their potential impact on VWF multimerization – Arijit Biswas, Hamideh Yadegari, Arshi Naz, Shariq Ahmed, Johannes Oldenburg
- Difference of major bleeding rate between hemophilia A and hemophilia B without inhibitors: a population-based, cohort study – Jiaan-Der Wang and Yu-Jer Tse
- The effect of non-neutralizing anti-drug antibodies on PK and bleeding rates in children less than 12 years of age with severe hemophilia A treated with RVIII-single chain – Helen Cathro, Katie St. Ledger, Annette Fuessner, Uwe Kalina, John Roberts, Tharin Limsakun, Nicole Blackman, Debra Bensen-Kennedy, Alex Veldman
- Combination therapy with CD20 antibody and Rapamycin for inhibitor reversal in hemophilia A: Preclinical evaluation – Moanaro Biswas, Haiyan Jiang, Roland Herzog
- Pharmacokinetics, safety, and efficacy of a new high-purity plasma-derived factor X concentrate in female subjects with hereditary factor X deficiency – Andra James, Amy Shapiro, Miranda Norton
- The global, multi-center, Phase III, Randomized, Efficacy, Pharmacokinetic and Safety Cross-Over Study (PERSEPT 1) of two dose regimens of Eptacog Beta (rhFVIIa) in congenital hemophilia A and B patients with inhibitors to cactor VIII or IX (HABI) – Michael Wang, Jeffry Lawrence, Doris Quon, Mark Reding, Jonathan Ducore, Mindy Simpson, Lisa Boggio, Johan Frielings, Allan Alexander, Jean-Francois Schved

S-W-07 – MULTIDISCIPLINARY

Adverse event reporting
HALL B3

Chair: Michael Makris, United Kingdom

- Why is it important to report adverse events? – Michael Makris, United Kingdom
- Current adverse event reporting in hemophilia – Alfonso Iorio, Canada
- How I maintain a registry and report adverse events – Nancy Brodie, United Kingdom
- Patient involvement in adverse event reporting – Thomas Sannie, France
**S-W-08 – MULTIDISCIPLINARY**

*Working with a bleeding disorder*

**ROOM 205**

**Chair:** Edward Kuebler, U.S.A.

- Patient from developing country – Pinsiri Godamunna, Sri Lanka
- Patient youth from developing country – Antonio Cavellini, Argentina
- Female patient from developing country – Baiba Ziemele, Latvia
- Female patient from developed country – Shelly Reed, U.S.A.

**S-W-09 – NURSING**

*Nursing orthopedic consideration*

**ROOM 206**

**Chair:** Kate Khair, United Kingdom

- Role of synovectomy – Mamoud Abu-Riash, Saudi Arabia
- Surgical case: Adult joint replacement – Lilijana Rakic, Serbia
- Nursing considerations: Managing surgery with long-acting products – Jen Maahs, U.S.A.
- Joint distraction: Ilizarov external fixator – Nanda Uitslager, the Netherlands
- Inhibitors and surgical case – Kun Rachel He, Canada

**S-W-10 – DENTAL**

*Novel technologies*

**ROOM 204**

**Chair:** Lochana Nanayakkara, United Kingdom

- Evidence base behind low level laser diode – Wayne Selting, U.S.A.
- Managing periodontal bleeding – Lochana Nanayakkara, United Kingdom
- Novel “technologies” in hematology for the care of people with hemophilia – Dan Hart, United Kingdom

**15:45–16:30**

**REFRESHMENT BREAK & MODERATED POSTER SESSIONS/POSTER VIEWING**

**MP-W-01 – MEDICAL**

*Moderated posters: inhibitors and laboratory issues*

**EXHIBIT HALL – CUBE A**

**Chair:** Marion Echenagucia, Venezuela

- Inhibitor risks in Argentine patients with severe HA. F8 genotype, status concordance in sibling pairs and immune gene polymorphisms studies – Claudia Pamela Radic, Vanina Marchione, Martin Abelleyro, Laura Primiani, Daniela Neme, Miguel de Tezanos Pinto, Carlos De Brasi, Liliana Rossetti
- Risk factors associated with high titre inhibitors development in Previously Untreated Hemophilia A patients (PUPS-HA) born between 2000 and 2013: A single center experience – Arlette Ruiz-Saez, Apsara Boadas, Marion Echenagucia, Julio Castro-Méndez
World-wide field study of FVIII activity assay variability of ADYNOVATE, the PEGylated form of rFVIII ADVATE, in clinical hemostasis laboratories – Peter L. Turecek, Claudia Apostol, Stefan Romeder-Finger, Alexander Bauer, Divan Burger, Herbert Gritsch

**MP-W-02 – MEDICAL**

*Moderated posters: Varia*

**EXHIBIT HALL – CUBE B**

**Chair:** Cedric Hermans, Belgium

- Algorithmic evidence-based phenotype screening and collaborative approach to attacking symptoms of nonadherence in patients with bleeding disorders – Jay Bryant-Wimp, Claudia Djambas Khayat, Georges Khayat, Bejjani Naim, Georges Tabet, Philippe De Moerloose, Alessandro Casini
- Effectiveness of the uPatient Platform in hemophilia prophylactic treatment – Rubén Cuesta-Barriuso, Ana Torres-Ortuño, José Antonio López-Pina, Joaquín Nieto-Munuera
- Management of US boys and girls with hemophilia B: Caregiver insights from the bridging hemophilia B experiences results and opportunities into solutions (B-HERO-S) study – Christine Guelcher, Michael Recht, Mary Frey, Robert Sidonio, Michelle Rice, Kimberly Haugstad, Natalia Holot, David L. Cooper

**MP-W-03 – MULTIDISCIPLINARY**

*Moderated posters: Varia*

**EXHIBIT HALL – CUBE C**

**Chair:** Marlène Beijleveld, the Netherlands

- Specific therapeutic support and development of the Body Schema in bleeding disorders – Herve Chambost, Natacha Rosso, Vincent Brejard, Yves Guillaume, Celine Falaise, Martine Roche, Jean-Christophe Bosq, Jean-Louis Pedinielli, Karine Baumstarck, Laurence Rasmussen
- Psychosocial care for children with congenital bleeding disorders and their parents in the Netherlands – Perrine Limperg, Lotte Haverman, Marlène Beijleveld, Karin Fijn van Draat, Marjolein Peters Martha Grootenhuis
- Tackling menorrhagia: A potential target to improve psychosocial wellbeing in women with bleeding disorders – Richa Mohan, Nita Radhakrishnan, Prachi Jain
**MP-W-04 – MULTIDISCIPLINARY**  
*Moderated posters: Women and bleeding disorders*  
**EXHIBIT HALL – CUBE D**

*Chair:* Roshni Kulkarni, U.S.A.
- A successful nine year journey by a China – Canada professional group to transfer current hemophilia assessment tools to advance pediatric hemophilia care in China – *Koon Hung Luke*, Man-Chiu Poon, Jing Sun, Runhui Wu, Lixia Chen, Pamela Hilliard, Brian Feldman, Nancy Young, Andrea Doria, Victor Blanchette
- Impact of Community Health Workers (CHWs) Training Programme to identify cases with bleeding disorder in South India – *Sulochana Badagabettu*, Anamma Kurien, Dinesh M Nayak, Veena Kamath, Asha Kamath
- The development of software for musculoskeletal evaluation database – *Janaina Ricciardi*, Márcia Matta, Glenda Feldberg, Carolina Costa-Lima, Samuel Medina, Margareth Ozelo

**16:30–18:00**

**CONCURRENT SESSIONS**

**S-W-11 – MEDICAL**  
*Von Willebrand disease*  
**HALL A4**

*Chair:* Andra James, U.S.A.
- Diagnosis – *Jereon Eikenboom*, the Netherlands
- Women’s issues – *Andra James*, U.S.A.
- Acquired VWD – *Augusto Federici*, Italy

**S-W-12 – MEDICAL**  
*Inhibitors : What have we learned?*  
**ROOM 206**

*Chairs:* Anneliese Hilger, Germany, and Mike Soucie, U.S.A.
- Data of the meta analysis of the 3 studies on recombinant products – *Brigitte Keller Stanislawsky*, Germany
- HIPs study: Investigator driven studies are the future to improve our understanding on immunogenicity – TBD
- PedNet study group – TBD

**S-W-13 – MULTIDISCIPLINARY**  
*Get net-smart: Privacy protection, assessment of online information, and using web-based tools in bleeding disorders care*  
**HALL B3**

*Chair:* David Silva-Gomez, Spain
- Assessing online educational material: Spotting the good, the bad, and the ugly – *Nancy Posel*, Canada
- Private screen/public domain: Maintaining security of personal health information – *Gary Bahadur*, U.S.A.
The virtual clinic experience: Benefits and challenges presented by electronic engagement between people with bleeding disorders and treatment centres... the view from both sides – Debra Gue, Canada; Paul Wilton, Canada
There’s an app for that! Highlighting available apps that augment the treatment of hemophilia – Thomas Schindl, Austria

S-W-14 – MULTIDISCIPLINARY
A winning team: Patients, healthcare providers, government, and industry
ROOM 205
Chair: Bruce Evatt, U.S.A.
- The government/funder perspective (health delivery system/most benefit for least cost) – Guilherm Genovez, Brazil
- The healthcare provider perspective (optimum/cost effective treatment within budget allocated) – Bruce Evatt, U.S.A.
- The industry perspective – Peter Pustoslemsek, Germany
- The WFH national members organizations' perspective – Ampaiwan Chuansumrit, Thailand

S-W-15 – MUSCULOSKELETAL
MSK issues for the ageing patient
ROOM 307
Chair: Sameer Rahim, South Africa
- Preventing falls: Outcome measures and techniques – Lorraine Flaherty, U.S.A.
- Are fractures an issue in the patient with hemophilia? – Horacio Caviglia, Argentina
- Engagement issues: Addressing participation in the ageing patient – Frederica Cassis, Brazil

S-W-16 – PSYCHOSOCIAL
Family caregiving and bleeding disorders: Helping parents cope
ROOM 204
Chair: Sylvia von Mackensen, Germany
- Interviews and results of questionnaires: Care Giver Burden Scale – Sylvia von Mackensen, Germany
- ‘Bouncing Back’: How to develop resilience in your child with a bleeding disorder – Linda Dockrill, New Zealand
- Family functioning – Moana Harlen, Australia
- Experience from a father’s perspective – Martin Grierson, Argentina
08:45–10:15

GENERAL PLENARY

PL-TH-01 – PLENARY

_Bleeding and Response to Treatment (How to Define a Bleed)_

**HALL A4**

**Chair:** Paul Giangrande, United Kingdom

- Patient view survey of different parts of the world – David Page, Canada
- Children who cannot speak for themselves – Kate Khair, United Kingdom
- Objective diagnosis of bleeds using ultrasound or other imaging – Annette von Drygalski, U.S.A.

10:15–10:45

REFRESHMENT BREAK
### 10:45-12:15

**CONCURRENT SESSIONS**

#### S-TH-01 – MEDICAL

**Late-breaking session**

**HALL A4**

Chair: TBD

#### S-TH-02 – MULTIDISCIPLINARY

**Ageing with hemophilia: Issues and challenges through different life stages**

**HALL B3**

Chair: Adolfo Llinas, Colombia

Panelists:
- 18–25 years old: Developing country – Ekawat Suwantaroj, Thailand
- 25–40 years old: Developing country – Sergii Shemets, Ukraine
- 50+ years old: Developed country – Val Bias, U.S.A.
- Psychologist – Anne Duffy, Ireland
- Orthopedist – Adolfo Llinas, Colombia
- Dentist – Andrew Brewer, United Kingdom

#### S-TH-03 – MUSCULOSKELETAL

**Challenging clinical cases: Tips and tricks from experts**

**ROOM 307**

Chairs: Mauricio Silva, U.S.A., and Greig Blamey, Canada

Topics:
- The hemophilic elbow: From pain pills to surgery
- Fixed knee flexion contracture: Evaluation and clinical management

Panelists:
- Orthopedist: Luigi Solimeno, Italy
- Hematologist: Paul Giangrande, United Kingdom
- Physiotherapist: Sharon Funk, U.S.A.

#### S-TH-04 – LABORATORY SCIENCES

**Diagnostic laboratory for hemophilia and other bleeding disorders in the management of hemorrhagic disorders**

**ROOM 204**

Chair: Sukesh Nair, India

- Laboratory management to control post-partum hemorrhage – Anne Riddell, United Kingdom
- Dengue hemorrhagic fever: Laboratory parameters and use of rFVIIa – Ampaiwan Chuansumrit, Thailand
- Importance of the quality of blood products in the management of hemorrhagic disorders: Role of a coagulation laboratory – Magdy El-Ekiaby, Egypt
S-TH-05 – NURSING

*Debate: Nurses Issues*

**ROOM 203**

**Chair:** James Munn, U.S.A.

**Topics:**
- Ports superior to peripheral venous access for children beginning home infusion
- Low-dose prophylaxis is effective as high-dose prophylaxis
- Short-term tertiary prophylaxis provides no benefit
- Women with hemophilia: Myth or reality?
- Neonatal circumcision in boys with hemophilia is child abuse

**Panelists:**
- Elaine Sandoval, Brazil
- BJ Ramsay, New Zealand
- Linda Myrin Westessen, Sweden
- Sulochana Badagabettu, India

S-TH-06 – PSYCHOSOCIAL

*Transition Challenges for Young Adults*

**ROOM 202**

**Chair:** Colleen McKay, New Zealand

**Topics:**
- Psychosocial issues – Dawn von Mayrhauser, U.S.A.
- Education and employment – Colleen McKay, New Zealand
- Youth patient perspective – Harshal Kale, India
- World perspective for challenges on young adults – David Silva, Spain

**12:15-13:45**

**WORLD FEDERATION OF HEMOPHILIA AWARDS**

**ROOM 205**

**19:00-24:00**

**FAREWELL DINNER**

Rosen Centre Hotel (Grand Ballroom)*

*Shuttle buses from/to the official Congress hotel (except the Hyatt Regency Hotel)