WFH GLOBAL POLICY AND ACCESS SUMMIT

VIRTUAL | October 27–28 2022

WFH
WORLD FEDERATION OF HEMOPHILIA

OCTOBER 27 – 28, 2022

DETAILED PROGRAM

Share strategies for sustaining and advancing bleeding disorders care now and in a post-pandemic world, **and promote dialogue and knowledge exchange** between national member organizations (NMOs), healthcare providers and national governments **to deliver better care.**

SESSION TYPES

PLENARY

Plenary sessions put the spotlight on our invited keynote speakers. Tune in for the latest news on bleeding disorders.

LIGHTNING ROUND SESSION

The Lightning Round sessions are intended to provide a fast-paced showcase of our National Member Organizations' advocacy initiatives around the world. Participants will present their 5 minutes video and will have 10 minutes to answer questions from the virtual audience.

WFH HIGHLIGHT SESSION

This session presents an overview of the advocacy initiatives from the WFH's Path to Access to Care and Treatment (PACT) Academy Program

EDUCATIONAL SESSION

Accessible to all members of the bleeding disorders community, these sessions aim to showcase educational content for all.

STAKEHOLDER DISCUSSIONS

These interactive sessions aim to bring together stakeholders to discuss strategies to improve delivery of care and develop sustainable access to treatment.
***By invitation only.**

- * BY INVITATION ONLY
- 🎧 INTERPRETATION AVAILABLE IN **SPANISH, FRENCH, RUSSIAN & ARABIC**
- 🕒 ALL TIMES ARE LISTED IN EASTERN DAYLIGHT TIME (EDT)
- ℹ PROGRAM IS SUBJECT TO CHANGE

THURSDAY, OCTOBER 27

08:30 - 09:00 OPENING PLENARY

Chair

Alain Baumann, CEO, World Federation of Hemophilia, Montreal, Canada

Opening and welcome remarks

Cesar Garrido, President, World Federation of Hemophilia, Caracas, Venezuela

The need for wise investments in health

Lieven Annemans, Senior Full Professor of Health Economics, ICHER, Ghent University, Ghent, Belgium

09:00 - 10:00 EDUCATIONAL SESSION

Decision making and influencing health policy

Chair

Dawn Rotellini, Chief Operating Officer, National Hemophilia Foundation, Gibsonia, United States

Healthcare models and decision making

Jamie O'Hara, CEO, HCD Economics, Daresbury, United Kingdom

Influencing healthcare budget for patient organizations

Bradley Rayner, Chairman, South African Haemophilia Foundation, Cape Town, South Africa

NMO role in promoting shared decision making

Clive Smith, Chair of the Board, The Haemophilia Society, London, United Kingdom

10:00 - 10:15 BREAK

10:15 - 11:15 LIGHTNING ROUND SESSION

Around the world in 60 minutes: What has worked well in advocacy initiatives and what are the lessons learned

Chair

Juan Andrés Pereira de Souza, Professor, Asociación De Hemofilia Del Uruguay, Montevideo, Uruguay

State-Based Advocacy Coalitions

Bill Robbie, Director, State Government Relations, National Hemophilia Foundation, New York, United States

Extension of Hemophilia Care throughout the Country; Barishal Division Example

Parimal Chandra Debnath, Vice President & PWH, Hemophilia Society of Bangladesh, Dhaka, Bangladesh

Strategic plan: Introduction of new therapies for Haemophilia A

Isabel Sorondo, President, Asociacion de Hemofilia del Uruguay, Montevideo, Uruguay
Juan Andrés Pereira de Souza, Professor, Asociación De Hemofilia Del Uruguay, Montevideo, Uruguay

The ICSPP (International Coalition for Safe Plasma Proteins) - leveraging partnerships and alliances with international organizations to improve access to safe plasma proteins in low- and middle- income countries

Jean-Claude Faber, President, Luxembourg Hemophilia Association (ALH), Luxembourg

Cont'd

Continued

11:15 - 12:15 EDUCATIONAL SESSION — Improving access: Data analysis to inform policy decisions 🎧

Chair

Kate Khair, Director of Research, Haemnet, London, United Kingdom

Data analysis to inform policy desicions

Declan Noone, President, European Haemophilia Consortium, Dublin, Ireland

A government perspective: Quality data for effective decision making

Jan Blatny, Vice President, EAHAD, Brno, Czech Republic

What data is needed to make informed decisions

Carisi Polanczyk, Head of Cardiology, Hospital Moinhos de Vento, Porto Alegre, Brazil

Case study: Developing bleeding disorder program and a new hemophilia unit model of new therapies

Victor Jimenez, Head of Hematology Department, Hospital Universitario La Paz, Madrid, Spain

12:15 - 12:30 BREAK

12:30 - 13:30 STAKEHOLDER DISCUSSIONS — Improving access to bleeding disorders care 🎧 *

* *By invitation only*

FRIDAY, OCTOBER 28

WORKING TOWARDS SUCCESS | DAY 2

07:00 - 08:00 STAKEHOLDER DISCUSSIONS

Improving access to bleeding disorders care 🎧 *

** By invitation only*

08:30 - 09:00 PLENARY

Improving standards of care 🎧

Chair

Salome Mekhuzla, Director - Global Development, World Federation of Hemophilia, Montreal, Canada

Demonstrating disparities in access to adequate care

Glenn Pierce, VP Medical, World Federation of Hemophilia, La Jolla, United States

Key principles and recommendations on improving standards of care

Johnny Mahlangu, Professor, University of the Witwatersrand and NHLS, Johannesburg, South Africa

09:00 - 10:00 EDUCATIONAL SESSION

Tackling inequities in access – Towards affordable care and treatment 🎧

Chair

Donna Coffin, Director, Research & Education, World Federation of Hemophilia, Montreal, Canada

Revisiting procurement models: Adapting to evolution in treatment

Brian O'Mahony, CEO, Irish Haemophilia Society, Dublin, Ireland

The WHO Model List of Essential Medicines: A tool to advise national procurement decisions

Bernadette Cappello, Technical Officer, Essential Medicines List Secretariat, World Health Organization, Geneva, Switzerland

NMO participation in the national procurement process: Serbia's experience

Dejan Petrovic, President, Serbian Hemophilia Society, Belgrade, Serbia

Inclusion of hemophilia in universal health coverage: Thailand's experience

Ekawat Suwantaroj, Vice President, Thai Hemophilia Patient Club - National Hemophilia Foundation of Thailand, Bangkok, Thailand

10:00 - 10:15 BREAK

10:15 - 11:15 WFH HIGHLIGHT SESSION

Advocacy initiatives from WFH PACT Advocacy Academy 🎧

Moderator

Salome Mekhuzla, Director - Global Development, World Federation of Hemophilia, Montreal, Canada

Overview

Julia Chadwick, Education Materials Coordinator, World Federation of Hemophilia, Montreal, Canada

Special person card for hemophilia patients

Usama Azam, Executive Member, Hemophilia Foundation Pakistan, Lahore, Pakistan

One law for all

Juan Andrés Pereira de Souza, Professor, Asociación De Hemofilia Del Uruguay, Montevideo, Uruguay

Procurement of Treatment Products for Hemophilia

Megan Adediran, Executive Director/ President, Hemophilia Foundation of Nigeria, Kaduna, Nigeria

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FRIDAY, OCTOBER 28

Continued

11:15 - 11:30 BREAK

11:30 - 12:30 EDUCATIONAL SESSION Tackling inequities in access: Industry perspective (panel) 🎧

Moderators

Glenn Pierce, VP Medical, World Federation of Hemophilia, La Jolla, United States

Dawn Rotellini, Chief Operating Officer, National Hemophilia Foundation, Gibsonia, United States

Panelists

BioMarin

CSL Behring

Kedrion Biopharma

Roche

Sanofi

12:30 - 13:00 CLOSING PLENARY 🎧

Chair

Alain Baumann, CEO, World Federation of Hemophilia, Montreal, Canada

Day 1 Stakeholders' Summary

Dawn Rotellini, Chief Operating Officer, National Hemophilia Foundation, Gibsonia, United States

Day 2 Stakeholders' Summary

Salome Mekhuzla, Director - Global Development, World Federation of Hemophilia, Montreal, Canada

Closing Remarks

Alain Baumann, CEO, World Federation of Hemophilia, Montreal, Canada