

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 in hemophilia.

### LIGHTNING ROUND SESSION

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### 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.**

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🎧 INTERPRETATION AVAILABLE IN **SPANISH, FRENCH, RUSSIAN & ARABIC**

🕒 ALL TIMES ARE LISTED IN EASTERN DAYLIGHT TIME (EDT)

📍 PROGRAM IS SUBJECT TO CHANGE

# THURSDAY, OCTOBER 27

## UNDERSTANDING THE POLICY LANDSCAPE | DAY 1

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*

### Investing in healthcare

*Lieven Annemans, Belgium, 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, Gibsonsia, United States*

### Healthcare models and decision making

*TBD*

### Influencing healthcare budget for patient organizing

*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*

11:15 - 12:15 EDUCATIONAL SESSION

Improving access: Data analysis to inform policy decisions

### Chair

*TBD*

### Data analysis to inform policy decisions

*Declan Noone, President, European Haemophilia Consortium, Brussels, Belgium*

### A government perspective: Quality data for effective decision making

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

### What data is needed to make informed decisions

*TBD*

### Developing bd program: Spain's case study

*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

*TBD*

#### **Demonstrating disparities in access to adequate care**

*Glenn Pierce, VP Medical, World Federation of Hemophilia, 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

*TBD*

#### **Revisiting procurement models: Adapting to evolution in treatment options**

*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 Healthcare coverage: Thailand's experience**

*Ekawat Suwantaroj, Lay Member, Board of Directors, World Federation of Hemophilia, Bangkok, Thailand*

10:00 - 10:15

BREAK

10:15 - 11:15

LIGHTNING ROUND SESSION

Advocacy Initiatives from PACT Advocacy Academy

### Moderator

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

11:15 - 11:30

BREAK

11:30 - 12:30

EDUCATIONAL SESSION

Tackling Inequities in Access: Industry perspective (Panel)

### Moderator

*TBD*

12:30 - 13:00

CLOSING PLENARY