



JULY 6 - 7, 2023

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 session is intended to provide a fast-paced showcase of our National Member Organizations' advocacy initiatives around the world. Featured NMOs will have 5 minutes to present their cases, following by a 20-minute question and answer period.

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)

 PROGRAM IS SUBJECT TO CHANGE

THURSDAY, JULY 6

TOWARDS EQUITABLE ACCESS | DAY 1

08:30 - 09:00

OPENING PLENARY

Towards equitable access



Join the opening plenary to hear about the GPAS objectives and the program highlights. Learn more about the WFH's work in areas of improving equitable access to diagnosis, treatment and care for people with bleeding disorders, regardless of their bleeding disorder, gender and where they live.

Chair

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

Opening remarks - Towards equitable access for all

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

Keynote address

Clive Ondari, Director of Health Products Policy and Standards, World Health Organization, Geneva, Switzerland

09:00 - 10:00

EDUCATIONAL SESSION

Disparities in access to diagnosis and care: A global snapshot



Access to diagnosis and care varies widely from country to country, region to region. Join our experts as they highlight global disparities in identification and diagnosis, access to therapies, access to prophylaxis, and more, with a special focus on the barriers faced by people with hemophilia, von Willebrand's disease and women and girls with bleeding disorders.

Chair

Rana Saifi, Regional Manager, Eastern Mediterranean, World Federation of Hemophilia, Montreal, Canada

Global disparities in access to diagnosis and care for PWBD

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

Barriers in accessing diagnosis and care for people with VWD

Nathan Connell, Chief of Medicine, Brigham and Women's Faulkner Hospital, Boston, United States

Barriers in accessing diagnosis and care for women and girls with bleeding disorders

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

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



Our National Member Organizations around the world are on the frontlines of advocacy for people with bleeding disorders. Join this session and hear more from our NMOs on some of the leading advocacy projects taking place in their countries to address the barriers in diagnosis and care. Get inspired as our featured presenters share their experience, lessons learned, and actionable recommendations you can implement today.

Chair

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

Advocating for the setting up of a prophylaxis network

Latifa Lamhene, Association Nationale des Hémophiles, Algeria

Path to prophylaxis in Egypt

Mohammed Soliman, Egyptian Society of Hemophilia, Egypt

Reduce the gap in diagnosis, treatment and care between women/girls and men/boys with BDs

Yannick Collé, Association Nationale des Hémophiles, France

Cont'd

Continued

Inclusion of haemophilia and other bleeding disorders patients into the National Council of Persons with Disabilities (NCPWD)

James Kago, Kenya Haemophilia Association, Kenya

Sudan: Sustaining access to care and treatment for patients with bleeding disorders during fighting in April-May 2023

Nawal Eltayeb MD, Sudanese Hemophilia Society, Sudan

Advocating for a focus on women with bleeding disorders in Syria's health care system

Tahani Ali MD, Syrian Hemophilia Society, Syria

All Copays Count Coalition

Bill Robie, National Hemophilia Foundation, United States

11:15 - 12:15

EDUCATIONAL SESSION

Strategies to accelerate identification and diagnosis of PWBD: Diagnosis - First step to access care



The WFH estimates that over 70% of expected people living with hemophilia worldwide have not yet been identified and diagnosed. Join this session to discover key findings from the WFH NMO survey on barriers to identification and diagnosis. Learn strategies to strengthen health care systems by looking at the role of primary healthcare, national screening programs, and recommendations from the WFH guidelines on hemophilia and VWD. Join the discussion as our panel of experts highlights successful outreach projects which have accelerated identification and diagnosis of PWBD.

Chair

Emna Gouider, Chief, Aziza Othmana Hospital- University Tunis El Mana, Tunis, Tunisia

Presentation of WFH NMO survey on barriers to identification and diagnosis

Juliana Hagembe, Outreach & Diagnosis Consultant, World Federation of Hemophilia, Nairobi, Kenya

Strengthening health systems to increase identification and diagnosis of PWBD

Adriana Velasquez Berumen, Team Lead Medical Devices and In Vitro Diagnostics, MDD, World Health Organization, Geneva, Switzerland

Panel discussion on strategies to accelerate identification and diagnosis of PWBD

Megan Adediran, Executive Director, Haemophilia Foundation of Nigeria, Kaduna, Nigeria

Mina (Kate) Hill, Haemophilia Nurse Co-Ordinator, South African Haemophilia Foundation, Cape Town, South Africa

Tahani Ali, Professor, Hematology & blood transfusion, Faculty of medicine, Damascus University, Damascus, Syria

12:15 - 12:30

BREAK

12:30 - 13:30

STAKEHOLDER DISCUSSIONS

Towards equitable access



★ *By invitation only*

FRIDAY, JULY 7

TOWARDS EQUITABLE ACCESS | DAY 2

07:00 - 08:00

STAKEHOLDER DISCUSSIONS

Towards equitable access



✦ *By invitation only*

08:30 - 09:30

EDUCATIONAL SESSION

Strengthening organization of care for bleeding disorders



How to ensure that patient organizations have a seat at the decision-making table? Join our keynote expert to uncover concrete strategies for successful advocacy to secure sustainable government investment for bleeding disorders. Learn about the multi-prong approach to strengthening care delivery systems by looking at WFH guidelines on national organization of care and recommendations on effective care delivery, national bleeding care programs and committees, and the vital role of the NMO in advancing the process. Learn about a captivating case study from Brazil which will cover the government perspective on developing national bleeding disorder programs.

Chair

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

Strategies to increase government investment in bleeding disorders

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

Strengthening care delivery systems

Alok Srivastava, Professor, Christian Medical College, Vellore, India

Government perspective on national bleeding disorder programs and/or a country case on including bleedign disorders in health policies

Erich Vinicius de Paula, Ministry of Health, Brazil

09:30 - 10:30

EDUCATIONAL SESSION

Tackling inequities in access in an era of therapeutic advances



Access to current therapies varies greatly around the world. The session will begin with an overview of currently available therapies and what's coming down the pipeline. Following this, an expert panel discussion will address the challenges of increasing equitable access in the fast-changing treatment landscape. Join the conversation to learn more about developments in novel therapies and what strategies should be put in place to increase equitable access to existing and novel therapies.

Chair

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

Overview of existing and novel therapies in bleeding disorders

Len Valentino, CEO, National Hemophilia Foundation, New York, United States

Panel discussion on increasing equitable access in era of a fast-changing treatment landscape

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

Len Valentino, CEO, National Hemophilia Foundation, New York, United States

Cedric Hermans, Head, Hemophilia Center, Cliniques Universitaires Saint-Luc, Woluwe-Saint-Lambert, Belgium

David Page, Director of Health Policy, Canadian Hemophilia Society, Montreal, Canada

10:30 - 10:45

BREAK

Cont'd

FRIDAY, JULY 7

TOWARDS EQUITABLE ACCESS | DAY 2

Continued

10:45 - 11:45

WFH HIGHLIGHT SESSION

Increasing equitable access:
PACT program



Launched in 2021, the WFH Path to Access to Care and Treatment (PACT) Program is designed to improve outreach and diagnosis and increase access to sustainable care for PWBD. Where are we two years in? Discover the progress made since 2021 towards achieving the PACT program goals. Learn more about the PACT Advocacy Academy 8-month long course and hear real-life stories from NMOs engaged in the PACT program as they share their outcomes and the impact of their participation on the bleeding disorders community in their country.

Chair

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

PACT Program objectives and 2 year progress

Guada Lagrada, Head - Regional Development, World Federation of Hemophilia, Montreal, Canada

PACT Advocacy Academy

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

Panel discussion: Impact stories from PACT countries

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

Flerida Hernandez, Physician, Hemophilia Association of the Philippines for Love and Service Inc., Manila, Philippines

Premroop Alva, President, Hemophilia Federation (India), New Delhi, India

Abdoulaye Loum, President, Association Sénégalaise des Hémophiles (ASH), Dakar, Senegal

11:45 - 12:45

EDUCATIONAL SESSION

Shared decision-making model in
healthcare



Learn about the SDM model and its value in enabling PWH to make informed treatment decisions alongside their healthcare team. Discover concrete examples of its successful application in other types of disease. Witness the global debut of the new WFH Shared Decision-Making tool for hemophilia. Learn how the the SDM model can be applied in clinical practice.

Chair

Courtney Thornburg, Medical Director, Hemophilia and Thrombosis Treatment Center at Rady Children's Hospital, San Diego, United States

Presentation on shared decision-making model in healthcare and its value

Mark Skinner, President and CEO, Institute for Policy Advancement Ltd, Washington, United States

WFH shared decision-making tool

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

Applying the shared decision-making model in clinical practice

Victor Jiménez-Yuste, Head of department, Hospital La Paz, Madrid, Spain

Applying the shared decision-making model as a patient

Bradley Rayner, Head of Programmes, South African Haemophilia Foundation, Cape Town, South Africa

12:45 - 13:00

CLOSING PLENARY



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

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