



**WFH**

**PACT  
PROGRAM**

**2023**

**IMPACT  
REPORT**



**WORLD FEDERATION OF HEMOPHILIA**  
FÉDÉRATION MONDIALE DE L'HÉMOFILIE  
FEDERACIÓN MUNDIAL DE HEMOFILIA



**PACT  
PROGRAM**

# MESSAGE FROM THE WFH (WORLD FEDERATION OF HEMOPHILIA)

Dear friends,

The World Federation of Hemophilia (WFH) vision of **Treatment for All** is for a world where all people with inherited bleeding disorders (PWBDs) have access to care, regardless of their type of bleeding disorder, gender, or where they live. The WFH Path to Access to Care and Treatment (PACT) Program was launched in 2021 to help meet this need. Today, as we reflect back on the first three years of this global initiative, we are proud of the positive impact this program has brought to the global inherited bleeding disorders community.

Last year was an exceptional one for the WFH PACT Program. In 2023, we expanded the global reach of the PACT Advocacy Academy—an online course for national member organization (NMO) leaders and advocates developed jointly with the New York University (NYU) Robert F. Wagner Graduate School of Public Service. For the first time, the course was offered not only in English, but also French and Spanish. We have also made significant strides in developing a dialogue and partnerships with national governments in many PACT countries to deliver better care.

The progress showcased in this impact report underscores the collective achievements of the WFH and its primary collaborators, alongside insights from program beneficiaries. These advancements are a testament to the unified dedication of our partners, which include WFH NMOs, healthcare providers, governmental collaborators, and industry affiliates.

We would like to extend our gratitude to the WFH team, and our PACT Advocacy Academy partners and expert working members for their exemplary professionalism and unwavering commitment to the WFH PACT Program:

- Emna Gouider, MD, WFH Board of Directors Medical Member (Tunisia)
- Mathieu Jackson, President, Quebec Chapter, Canadian Hemophilia Society (Canada)
- Brian O'Mahony, Chief Executive, Irish Hemophilia Society (Ireland)
- Carlos Safadi Márquez, WFH Vice President, NMO (Argentina)
- David Elcott, Henry and Marilyn Taub Professor of Practice in Public Service and Leadership, NYU (U.S.A.)
- John Gershman, Clinical Professor of Public Service, NYU (U.S.A.)

We anticipate the forthcoming years with optimism as we continue advancing towards the goals of the WFH PACT Program. These objectives aim to enhance outreach and diagnosis while expanding access to enduring care for people with bleeding disorders worldwide.



**Cesar Garrido**  
President



**Alain Baumann**  
CEO



**Salome Mekhuzla**  
Director, Global  
Development

# THE WFH PATH TO ACCESS TO CARE AND TREATMENT (PACT) PROGRAM

The WFH PACT Program is a five-year initiative designed to improve outreach and diagnosis and increase access to sustainable care for PWBDs. This will be achieved through training, education, partnerships, in-country initiatives, and evidence-based advocacy.

Over 5 years, the PACT Program aims to:

**1 IDENTIFY** 20,000 new PWBDs in the 20 targeted countries

**2 IMPROVE** access to care through training and education.

**3 INCREASE** government support to establish or expand existing national bleeding disorders care programs

The program is implemented through three key components (2021–2025):



## ONLINE TRAINING AND EDUCATION

The **PACT Advocacy Academy** to give NMO leaders and patient advocates the necessary knowledge and skills they need to carry out successful evidence-based advocacy campaigns.

**Annual virtual training sessions** for healthcare practitioners (HCPs) focused on outreach, diagnosis, and the management of bleeding disorders.



## NATIONAL ACCESS PLANS

**Tailored 4 or 5-year national access plans** including personalized training, and on-the-ground support for outreach and advocacy projects to increase support from national governments.

**Mentorship from subject-matter experts** for NMO leaders in target countries supporting the implementation of national access plans; also, guidance for PACT Advocacy Academy participants.



## GLOBAL AND REGIONAL MEETINGS

**Global and regional training and meetings** to share best practices on evidence-based advocacy between community leaders and promote dialogue and engagement between key stakeholders.

# PACT ON THE GROUND

Twenty countries worldwide participate in the WFH PACT Program. As part of the program, each PACT country develops a national access plan that includes personalized training, and outreach and advocacy campaigns to increase support from national governments for bleeding disorders programs. The program also maintains a global reach through training and outreach activities.



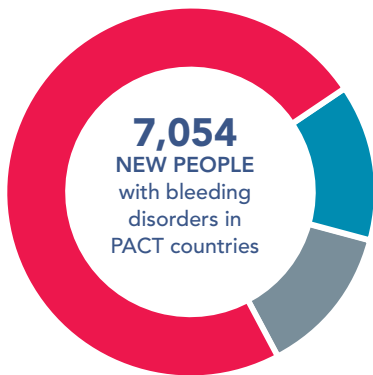
Community Health Workers training in Kisii County, Kenya

# 2023 WFH PACT PROGRAM –PROGRESS CASE STUDIES

**OBJECTIVE 1: IDENTIFY** 20,000 new people with bleeding disorders in the 20 targeted countries (2021–2025).

Accurate diagnosis is the first step in accessing treatment and care. Increasing identification of new PWBDs is one of the main objectives of the WFH PACT Program. As more individuals are identified and included in patient registries, the bleeding disorders community grows, and patient voices are amplified. This in turn helps to demonstrate the need for sustainable care and treatment.

The number of newly identified PWBDs reported in PACT countries reached 7,054 in 2023.



People with hemophilia: 5,188

von Willebrand disease (VWD): 954

Other bleeding disorders: 912

The WFH PACT program supported a series of national initiatives directed towards increasing identification rates in participating countries. These initiatives included laboratory diagnosis workshops, outreach activities, the education of healthcare professionals and community health workers, the improvement of local data collection capacities, and the expansion of the World Bleeding Disorders Registry (WBDR) platform usage. Opposite are a few selected examples of relevant national initiatives.



Community Health Workers Outreach session in Akure, Nigeria



Awareness program on bleeding disorders at PTV, Pakistan

**BANGLADESH** 385 new people with hemophilia were identified in 2023. Tailored HCP training and outreach activities were coupled with the expansion of the HTC network to all regions of the country. Compared to their starting point before the launch of the WFH PACT Program in Bangladesh, the number of people with bleeding disorders identified in the country has increased by 45% in the first three years of the program, already surpassing the 5-year target.

**INDIA** Two hands-on regional laboratory diagnosis workshops were organized to train 60 laboratory specialists from 19 HTCs across the country, expanding the much-needed availability of diagnosis. These trainings—along with outreach efforts by the NMO—have contributed to the identification of 827 new PWBDs in the country last year. This has allowed India to surpass its overall 5-year target with a cumulative number of 5,698 newly identified PWBDs reported in the country from 2021 to 2023.

**EGYPT** A laboratory training workshop was held which resulted in basic coagulation tests now being available in four HTCs outside Cairo, helping expand diagnostic capacity in the regions. The lab workshop also focused on inhibitor testing. Overall, these and other capacity building and outreach efforts in have resulted in identification of 463 new PWBDs in Egypt last year.

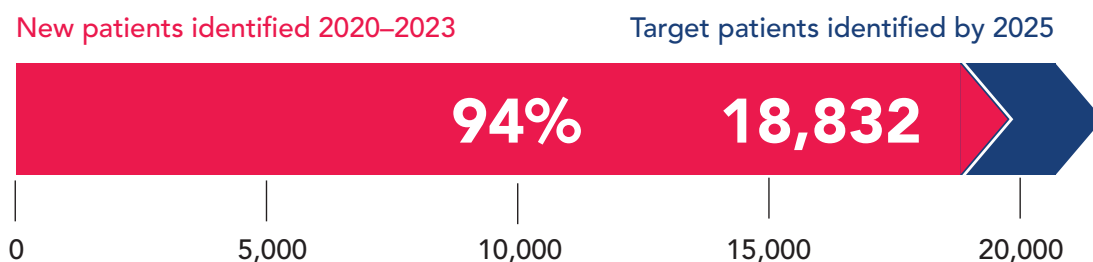
**INDONESIA** A data collection workshop was organized for 20 representatives from the Indonesia Hemophilia Society’s chapters with the objective of improving data collection on bleeding disorders across the country. Capacity to report quality data is pivotal in expanding national registries. 354 new PWBDs were reported in Indonesia last year.

**KENYA** Significant efforts were made to expand the training of 324 community health workers throughout the country, including trainings held in Bungoma, Kisii, Dandora and Meru counties. The Kenya Hemophilia Association also reached an agreement to jointly develop a standardized bleeding disorders training manual that is currently underway and will be included in the official training program for community health workers.

**NEPAL** Two educational workshops were held for over 100 community health workers in 2023. Topics covered included the main symptoms of hemophilia, inheritance pattern, family tree mapping and basic care and treatment.

**NIGERIA** Two training sessions for nurses and two outreach workshops for community health workers were organized across several states of Nigeria with the aim to raise awareness on bleeding disorders and support identification and diagnosis efforts. 80 new PWBDs were identified in the country last year.

**VIETNAM** A two-part series of virtual workshops were organized on key components of outreach and diagnosis to revisit existing outreach initiatives and identify more effective strategies to accelerate identification rates in the country. 36 healthcare professionals from ten HTCs and NMO leadership attended the workshops.



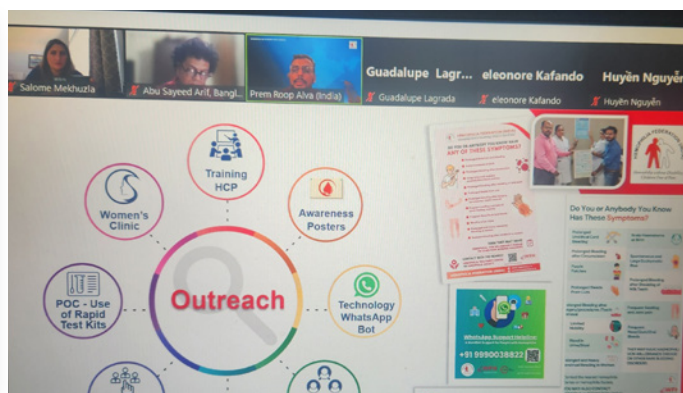
# 2023 WFH PACT PROGRAM –PROGRESS CASE STUDIES

**OBJECTIVE 2: IMPROVE** access to care through the training and education of patient leaders and HCPs globally in outreach, diagnosis, the management of bleeding disorders, and evidence-based advocacy.

The WFH PACT Program’s education and capacity-building initiatives help to increase equitable access to diagnosis, treatment, and care at the national and global levels.

## Virtual trainings

The 2023 PACT virtual training sessions were held for 160 HCPs and NMO members focusing on the development of effective outreach and diagnosis projects. Participant feedback also helped validate the new standardized training curriculum recently developed by the WFH.



WFH Outreach and Diagnosis Webinar Series

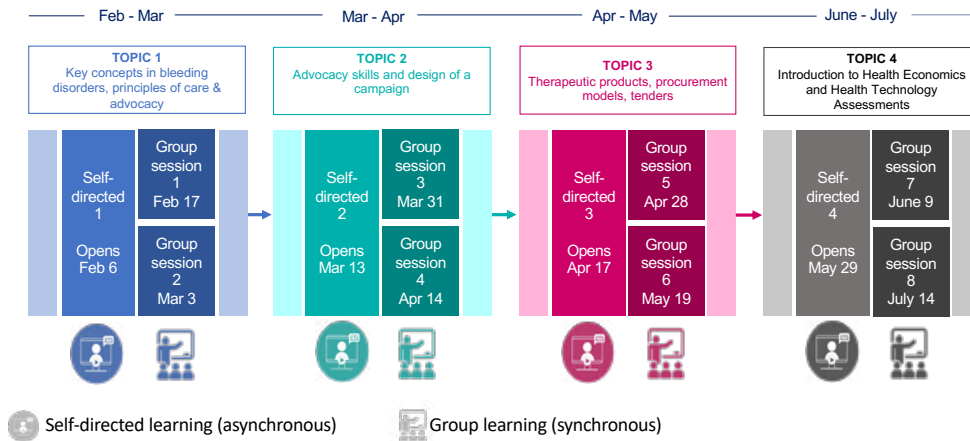
## The PACT Advocacy Academy

The second PACT Advocacy Academy cohort—made up of 28 participants from 20 countries—completed their course in 2023. For eight months, the participants took part in the four main learning modules created by the WFH in collaboration with the New York University Robert F. Wagner Graduate School of Public Service. These modules covered key concepts in bleeding disorders, principles of care, advocacy skills, campaign design, introduction to health economics and health technology assessments, and key concepts in therapeutic products, procurement models, and tenders.

Offering the course in French and Spanish in addition to English helped expand the global reach of the PACT Advocacy Academy. In addition to attending the live interactive sessions and completing self-directed online learning modules, the participants developed their own real-life advocacy projects and received guidance from course faculty. They were also mentored by advocacy and bleeding disorders experts.



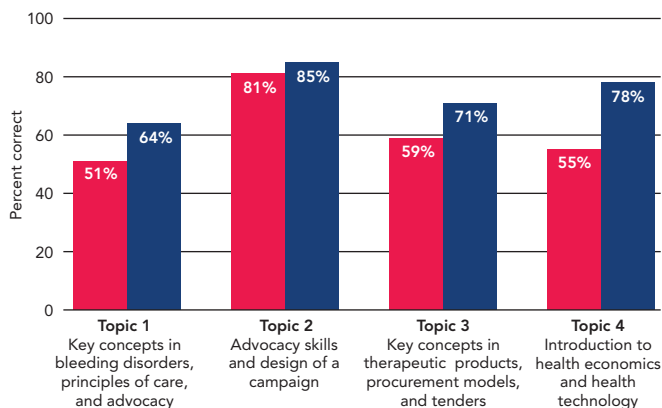
# 2023 PACT Advocacy Academy



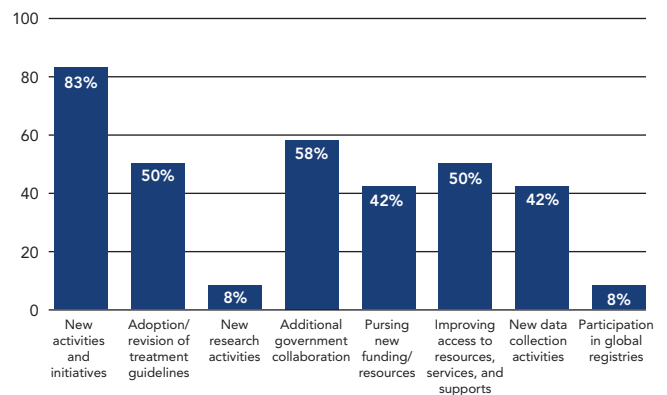
2023 cohort participants have demonstrated an increase in knowledge related to all course modules, as highlighted in the pre- and post-session quizzes. Participants have also expressed positive feedback on the usefulness of the course and the enriching learning opportunities provided by the faculty, mentors, and fellow participants.

In addition to 2023 cohort evaluation and feedback, we also surveyed the 2022 cohort participants 12 months after graduating from the course to understand what impact the PACT Advocacy Academy had on their advocacy work and overall programs and initiatives of their NMOs. According to the findings of this evaluation, 82% of the respondents have stated that they implemented their advocacy projects developed as part of the course. 83% of the respondents also reported their NMOs having launched new activities and initiatives and 58% having increased government collaboration among other outcomes.

PACT Advocacy Academy 2023 Cohort: Average Increase in Knowledge of the Participants



What was the impact of the PACT Advocacy Academy Course Impact on NMO? (Multiple answers permitted)



# 2023 WFH PACT PROGRAM –PROGRESS CASE STUDIES

“My biggest learnings from the PACT Advocacy Academy were being able to access technical information... For example, being able to know how the IU per capita indicators are constructed or what the approval or monitoring system for a drug is like ... I have applied strategic thinking, analyzing pharmaco-economics or health technology assessment (HTA) issues that I did not take into account before... We have had some achievements. For example, being able to present to industry to obtain financing for an Annual Advocacy Plan and lobbying to obtain prophylactic treatment for those over 21 years of age. We have received support from several industry partners, and we will begin execution in May...”

Antonio Gómez Cavallini, Fundación de la Hemofilia, Argentina, 2023 cohort

“One of the main learnings for me from the PACT Advocacy Academy was using systemic thinking to manage advocacy projects. I have applied stakeholder analysis in my advocacy work and conducted workshops about stakeholder mapping... to share my learnings with the Thai hemophilia youth group and with other rare disease patient groups.”

Ekawat Suwataroj, Thai Hemophilia Club, Thai Hemophilia Foundation, Thailand, 2023 cohort

“After completing my course, I felt more confident and started to be involved [in my NMO] more actively. I started to communicate with government decision-makers, was involved in making a strategic plan for a treatment plan for people with hemophilia (PWH) which helped us achieve a significant increase of budget for the procurement of treatment products...”

Aizat Aidarbekova, Community of Handicapped Hemophiliacs, Kyrgyzstan, 2022 cohort

## Global reach of the PACT Advocacy Academy 2022–2023 cohorts



## In-country trainings

Numerous training and educational activities were conducted locally in PACT countries to raise awareness among NMO members, PWBDs and their families to motivate and empower the community to advocate for better care and treatment for all. In addition to this, various targeted training sessions were organized to enhance knowledge and skills of healthcare professionals in the clinical management of bleeding disorders.

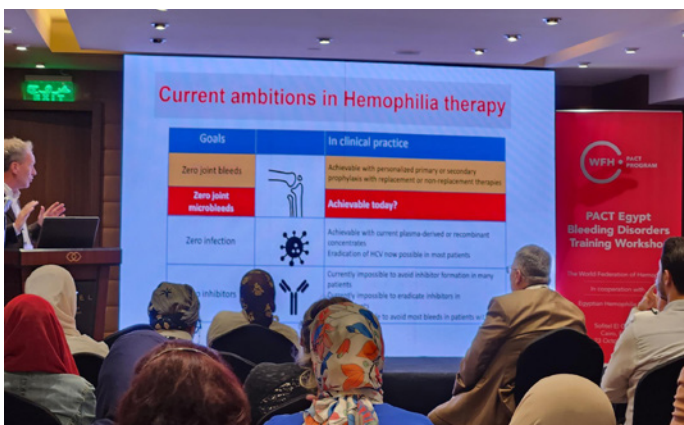
**CHINA** Three national workshops were organized by the Hemophilia Treatment Centers Cooperative Network of China in collaboration with the WFH. Pediatricians, physiotherapists, rehabilitation specialists, and nurses from all over the country came to improve comprehensive care for people with hemophilia. In addition to this, a nurses’ workshop introduced the process of training and certification of hemophilia nurses.

**PAKISTAN** Several educational and awareness-raising initiatives were conducted in different provinces of Pakistan for healthcare professionals, patients and their families. One of them was a dedicated workshop on the management of women and girls with bleeding disorders and von Willebrand disease (VWD), held in Rawalpindi, and attended by over 80 hematologists, gynecologists, patients and parents. Other educational workshops included a dental workshop, a diagnosis workshop and other workshops on hemophilia and VWD management.

**EGYPT** Building on the experience of the nurses training workshop organized in 2022 in Egypt—organized by the WFH in partnership with the World Health Organization (WHO) Egypt Country office—a follow up training was offered to nurses to advance their competencies. In addition to this, training workshops were conducted for dentists, clinicians and laboratory specialists.

“The long-standing history of cooperation between the WFH and the Egyptian hemophilia community was key to integrating hemophilia care into the national health program. In 2023, the WFH PACT Program helped increase the capacity to implement universal prophylaxis for patients under 18 years old. The Program also supported the publication of the second edition of the Egyptian Guidelines on the Management of Hemophilia and the National Consensus on the Management of Inhibitors.”

Magdy El-Ekiaby, MD, Vice President of the Egyptian Society of Hemophilia (ESH)



Workshop on clinical management of bleeding disorders, Egypt



Workshop for physiotherapists, India

# 2023 WFH PACT PROGRAM –PROGRESS CASE STUDIES

**INDIA** Two MSK workshops were organized in Hyderabad and Pune with the participation of 78 physiotherapists from ten states in India. A World Hemophilia Day celebration was also marked by launch of a WhatsApp bot: a patient support application designed to help patients access basic treatment information, and list of HTC's and NMO chapters.

**INDONESIA** Following the launch of its national treatment guidelines in 2022, the Indonesian Hemophilia Society has continued its efforts to implement the guidelines through a collaborative multicenter pilot project on low-dose prophylaxis being implemented by six main HTCs. Educational workshops were also conducted for healthcare professionals on comprehensive care, home treatment, and hemophilia joint health.

**MEXICO** The Mexican national hemophilia congress brought together close to 600 healthcare professionals, PWBDs and their families. The event included medical, MSK and psychosocial tracks.



MSK workshop for patients, Mexico



Awareness raising on hemophilia and VWD, Senegal

## NMO Capacity Development

Strengthening the organizational capacities of WFH NMOs is one of the priorities of the WFH PACT Program. The NMOs in Argentina, Indonesia and Malaysia conducted capacity development self-assessments that have helped identify organizational strengths and areas in need of further development. Specific action plans addressing various organizational development components were also outlined as part of this exercise.



NMO capacity assessment workshop, Indonesia



NMO capacity assessment workshop, Malaysia

As part of the WFH PACT program, participating NMOs can receive advisory support from bleeding disorders and advocacy mentors. In 2023, Brian O'Mahony provided guidance and expertise to the NMO in Argentina on effective advocacy strategies to increase government investment in bleeding disorders care. He also participated in the NMO capacity development self-assessment workshop and accompanied the NMO along with the WFH team in discussions with parliament members and the Ministry of Health.



Meeting with the Ministry of Health, Argentina

# 2023 WFH PACT PROGRAM –PROGRESS CASE STUDIES

**OBJECTIVE 3: INCREASE** government support to establish or expand existing national bleeding disorders care programs.

Forging collaboration between NMOs, country partners, government agencies and other institutions in capacity building and outreach is a key element of the WFH PACT Program. The Program supports in-country evidence-based advocacy initiatives and collaborative engagements with governments and other stakeholders. This approach continues to yield positive results for the bleeding disorders community.

## Agreements and Memorandums of Understanding

The signing of a Memorandum of Understanding (MoU) between the WFH and the governments of Zambia and Egypt are two milestone achievements. Setting a formal partnership framework with the governments through an MoU amplifies government support and sets up a long-lasting commitment to increasing equitable access to diagnosis, treatment and care.

## Policy changes and increased government investment in treatment and care

Joint efforts of NMOs, HCPs, and the WFH have resulted in tangible progress towards having bleeding disorders recognized as a government priority in several PACT countries. This is an important step for more robust collaboration with governments and policy changes in the coming years.

### The WFH PACT Program: new Memorandum of Understanding signed in Zambia

In February 2023, the WFH and the Ministry of Health (MoH) in Zambia signed a MoU to implement the WFH PACT Program. The Program aims to improve diagnosis, treatment, and care for people with bleeding disorders in Zambia. The MoU is the result of ten years of outreach and advocacy work by the Haemophilia Foundation of Zambia (HFZ), under the leadership of Chairperson Charity Pikiti, and in collaboration with the WFH and the MoH.

“The level of care in Zambia has increased significantly over the last few years, thanks to the hard work of many committed stakeholders. The signing of this MoU signifies an exciting new chapter in this journey.”

Cesar Garrido, President, WFH

## The WFH PACT Program: new Memorandum of Understanding signed in Egypt

In October 2023, a trilateral MOU was signed for the WFH PACT Program partnership between the WFH, the Egyptian Ministry of Health (MOH) and the Egyptian Society of Hemophilia (ESH). The MOU was ratified in Cairo by Cesar Garrido, WFH President; Mohamed Al Sayed Dahy, MD, Chairman of the Health Insurance Organization (HIO) on behalf of the MOH; and Magdy El-Ekiaby, MD, Vice President of the ESH. The MOU represents a new milestone in a more than two-decade-long collaboration.



PACT MOU signing ceremony, Egypt

**BANGLADESH** The government continues to support hemophilia care as part of its Second Operation Plan of Noncommunicable Disease Control, securing an annual budget allocation for bleeding disorders care with specific objectives set for the identification of new PWBDs and the dissemination of information about bleeding disorders. The results of increased government support are reflected in accelerated identification, notable increase in budget allocated for procurement of therapeutic products and expansion of the network of HTC in the country, where now there is at least one HTC in each regional division.

**SENEGAL** Association Sénégalaise des Hémophiles (ASH), through its advocacy work, fostered stronger collaboration with the Ministry of Health (MOH), resulting in the integration of hemophilia into the government's healthcare strategic plans—highlighted as the second objective in “Le Plan National de Développement Sanitaire” and “Le Plan stratégique de lutte contre les Maladies non-transmissibles”. This means that more government resources will now be allocated to hemophilia care. One of the key factors that contributed to this outcome was the inclusion of representatives from the Ministry and the national blood transfusion institute along with ASH in the WFH PACT Program technical working group from the onset of the program. The PACT National Access Plan in Senegal was co-created with these key stakeholders and was subsequently integrated into the Senegal Alliance of non-communicable diseases’ “Accelerating plan for fighting against NCDs 2023-2025”.

“The Ministry of Health understands the importance of patient associations. This is reflected in the sustained support we receive from the directorate of NCDs and the hemophilia treatment centre (HTC)—the Centre National de Transfusion Sanguine (CNTS)—for our important activities. The WFH PACT Program provides us with an opportunity to better collaborate as a partner with the Ministry and increase our visibility and leadership in the country.”

Abdoulaye Loum, President of the Association Sénégalaise des Hémophiles (ASH)

# 2023 WFH PACT PROGRAM –PROGRESS CASE STUDIES

**BRAZIL** Federação Brasileira de Hemofilia and the WFH have engaged in systematic dialogue with key government healthcare decision makers in the country. These targeted efforts have been part of the advocacy strategy and have contributed to consistent increase in national procurement of CFCs and non-factor replacement therapies in Brazil reported in the past two years.

**PAKISTAN** As a result of successful advocacy efforts of the Hemophilia Foundation of Pakistan and its Karachi chapter, the provincial government increased the amount of the grant awarded to the Hemophilia Welfare Society of Karachi, enabling it to procure treatment products, particularly non-factor replacement therapies.

**ZAMBIA** The Ministry of Health of Zambia has formally recognized hemophilia as a priority through the signing of a WFH PACT Program Memorandum of Understanding February 2023.



Meeting with government officials during the WFH visit, Brazil



World Hemophilia Day Congress opening ceremony with Social Security Institute representatives, Mexico

## National guidelines

Training and education initiatives have contributed to stronger collaborative networks of HCPs, which is an important factor in improving care delivery. With the support of the WFH PACT Program, several participating countries have established working groups and/or initiated formal consultations to facilitate developing national guidelines and protocols for the management of bleeding disorders.

**EGYPT** In 2023, the WFH supported the development of national treatment guidelines and a consensus paper on immune tolerance induction (ITI). The WFH team also actively participated in national conferences, including the annual Egyptian Society for Pediatric Hematology and Oncology (ESPHO) conference.

**BOLIVIA** A national hemophilia meeting was organized with the participation of key stakeholders, including the NMO, patient leaders, healthcare professionals and government representatives. Options to improve data collection and sharing were discussed and an agreement was reached to develop national treatment guidelines in 2024. A discussion to finalize an MOU between the WFH and the Bolivia Ministry of Health also progressed, with the MOU expected to be signed in 2024.



**MEXICO** Treatment protocols were developed for patients managed under the social security system in Mexico. These protocols cover access to treatment, including prophylaxis and novel therapies, as well as criteria for surgical interventions and physiotherapy.

**SENEGAL** National guidelines for management of hemophilia were developed and adopted.

**VIETNAM** National guidelines for management of hemophilia were also updated in Vietnam. They will be officially adopted by the healthcare authorities in the beginning of 2024.

“The collaboration between our chapters and government HTC’s has helped to increase the number of diagnostic centres. It has also helped [HFI] chapters improve their understanding of the importance of data and the importance of sending National Hemophilia Registry data on a regular basis. The governments of several states are looking forward to the launch of our national treatment guidelines.”

Premroop Alva, President, Hemophilia Federation India

## LIST OF PACT COUNTRIES AND NMOs

PACT Country	NMO	PACT Country	NMO
Argentina	Fundación de la Hemofilia	Malaysia	Hemophilia Society of Malaysia
Bangladesh	Hemophilia Society of Bangladesh	Mexico	Federación de Hemofilia de la República Mexicana
Bolivia	Fundación Nacional de Hemofilia Bolivia	Nepal	Nepal Hemophilia Society
Brazil	Federação Brasileira de Hemofilia	Nicaragua	Asociación Nicaragüense de Hemofilia
China	Hemophilia Treatment Center Collaborative Network of China	Nigeria	Hemophilia Foundation of Nigeria
Costa Rica	Asociación Costarricense de Hemofilia	Pakistan	Hemophilia Foundation-Pakistan
Egypt	Egyptian Society of Hemophilia	Palestine	Avenir Foundation
India	Hemophilia Federation India	Senegal	Association Sénégalaise des Hémophiles
Indonesia	Indonesia Indonesian Society of Hematology and Blood Transfusion	Vietnam	Vietnam Hemophilia Association
Kenya	Kenya Hemophilia Association	Zambia	Haemophilia Foundation of Zambia

# LOOKING AHEAD

2023 marks the midpoint of the WFH PACT Program's 5-year plan. Midpoint evaluations were conducted in several PACT countries to assess progress made, the challenges encountered, and to review the national plans.

## Online training and education

We will continue to offer the PACT Advocacy academy course in English, French and Spanish in 2024. A review of the outcomes of the advocacy campaigns of the participants of the 2023 cohort will also be conducted for learning and sharing.

In the third quarter, the WFH will host virtual workshops for HCPs and bleeding disorders community leaders from the 20 PACT countries. These workshops will focus on various aspects of management of bleeding disorders.

## National access plans

All 20 PACT countries will continue implementing their National Access Plans to make progress towards their five-year targets. The political instabilities in Nicaragua and the ongoing Palestine conflict will have an impact on the implementation of planned in-country initiatives. The WFH remains committed to continue supporting bleeding disorders communities in these countries. After a thorough assessment— and after having conducted a capacity assessment workshop—the WFH has invited Uzbekistan to join the WFH PACT Program for the years 2024 to 2025. Furthermore, the WFH will continue to offer mentorship opportunities to support NMOs on specific aspects of their respective national plans.

## Global and regional meetings

A WFH PACT Program session will be organized during the 4<sup>th</sup> WFH Global Policy and Access Summit planned to take place from September 26 to 27, 2024. This session will highlight the impact of the WFH PACT Program, and showcase participating NMOs and PACT Advocacy Academy graduates, their advocacy projects, outcomes and lessons learned.

Thank you to the WFH PACT Program partners for their invaluable support in 2023

VISIONARY PARTNER



LEADERSHIP PARTNERS



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