



WFH

**PACT
PROGRAM**

2021-2025

**IMPACT
REPORT**



WFH

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



**PACT
PROGRAM**

MESSAGE FROM THE WORLD FEDERATION OF HEMOPHILIA (WFH)

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. In alignment with this vision, the WFH launched the Path to Access to Care and Treatment (PACT) Program in 2021 to address existing disparities in diagnosis and inequitable treatment and care provision worldwide. Today, we are proud of the positive impact this program has brought to the global inherited bleeding disorders community during its first five years.

The program made significant progress during 2021-2025. Notably, the five-year objective of identifying 20,000 new people with bleeding disorders (PWBDs) across 20 PACT countries was significantly surpassed. Also, the fourth cohort of the PACT Advocacy Academy successfully completed its training. This online course, developed in partnership with the New York University (NYU) Robert F. Wagner Graduate School of Public Service, has graduated four cohorts of leaders and advocates from WFH national member organizations (NMOs) during 2021-2025, who are now better equipped with knowledge of bleeding disorders treatment and care standards and effective advocacy skills.

In addition, the PACT program has fostered stronger dialogue and partnerships with national governments in participating countries, facilitating progress toward strengthening national health systems and improving care delivery for those with inherited bleeding disorders.

The outcomes presented in this report are the result of collective efforts by the WFH, NMOs, healthcare professionals, government stakeholders, and industry partners. Their shared commitment has contributed meaningfully to advancing care and access for the global bleeding disorders community.

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

- Emna Gouider, MD, WFH Vice President, NMO (Tunisia)
- Mathieu Jackson, WFH Board Member (Canada)
- Brian O'Mahony, Chief Executive Officer, Irish Hemophilia Society (Ireland)
- Carlos Safadi Márquez, Hemophilia Foundation of Argentina (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.)

As we reflect on the results of the first five years of the program, we look ahead with anticipation for the next phase of the PACT program during 2026-2030 in service of the WFH mission at large.



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 was designed to improve outreach and diagnosis and increase access to sustainable care for PWBDs. This is achieved through training, education, partnerships, in-country initiatives, and evidence-based advocacy.

Over five years, the WFH 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 to 2025):



ONLINE TRAINING AND EDUCATION

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

Annual virtual training sessions for healthcare professionals (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 to promote dialogue and engagement between key stakeholders.

PACT ON THE GROUND

The following countries were enrolled in PACT program during 2021-2025: Argentina, Bangladesh, Bolivia, Brazil, China, Costa Rica, Egypt, India, Indonesia, Kenya, Malaysia, Mexico, Nepal, Nigeria, Pakistan, Palestine, Senegal, Uzbekistan (replaced Nicaragua that was originally enrolled in PACT program, but we had to cease the program due to local political instabilities), Vietnam, and Zambia. Tailored 4- or 5-year national plans were implemented in each participating country. In addition, PACT program's reach was expanded through capacity-building provided to NMO leaders and advocates through PACT Advocacy Academy. The program also maintained a global reach through training and educational activities, as well as the PACT Advocacy Academy.



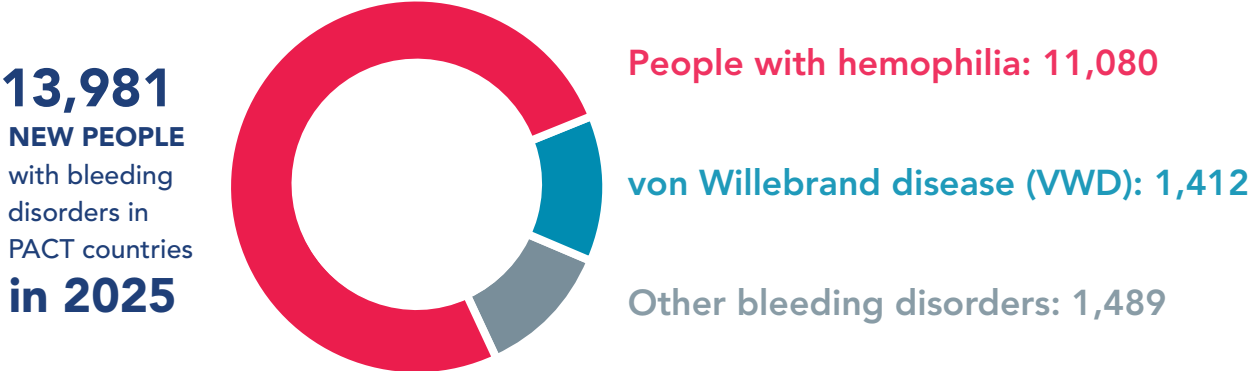
Bleeding disorders education session in Mandera, Kenya

WFH PACT PROGRAM – HIGHLIGHTS AND KEY OUTCOMES

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

Increasing the identification and diagnosis of new PWBDs was one of the main objectives of the WFH PACT Program. As more individuals are identified and included in national registries each year, our community grows and a stronger case can be made for sustainable treatment and care.

The number of newly identified PWBDs reported in 20 PACT countries reached 13,981 in 2025.

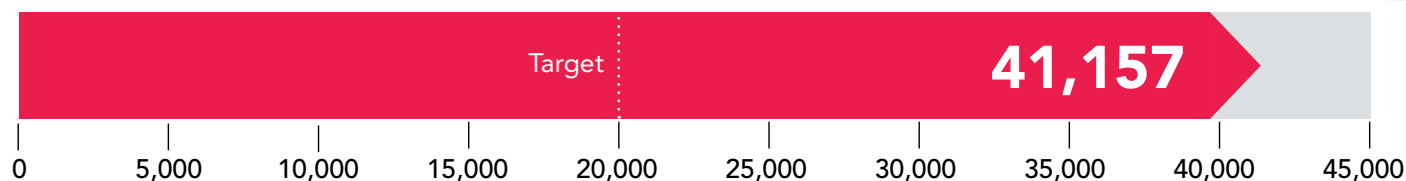


The WFH PACT program supported various in-country initiatives focusing on strengthening laboratory diagnosis capacity, outreach, identification, data collection and national registries. These initiatives included laboratory diagnosis workshops, outreach and awareness-raising activities, the education of healthcare professionals and community health workers, the strengthening of local data collection capacities and mechanisms, and the expansion of the World Bleeding Disorders Registry (WBDR) usage. Below are a few selected examples of relevant national initiatives.



Patient evaluation during HCPs workshop, Vietnam

Overall, during 2021-2025, 41,157 newly identified people with bleeding disorders have been reported in PACT countries, significantly surpassing the 5-year goal of 20,000 newly identified patients.



BRAZIL Federação Brasileira de Hemofilia translated the third edition of WFH Diagnosis of Hemophilia and Other Bleeding Disorders: Laboratory Manual into Portuguese. This new manual was distributed to hemostasis laboratories of HTC across the country. They were also shared with HTCs in other Portuguese-speaking countries.

CHINA Hemophilia Treatment Centres Collaborative Network of China continued to expand its network of treatment centres and enhance knowledge and awareness on management of bleeding disorders among the medical community. Through the national HTCs accreditation program, the HTCCNC has increased the number of hospitals accredited as HTCs from 38 to 192 during 2021-2025, including 12 accredited as comprehensive case centres, 38 diagnosis and treatment centres and 141 hemophilia treatment centres, expanding access to diagnosis and treatment throughout the country. These efforts along with regular updating of the national registry and increased patient education and engagement with various patient groups in the country have resulted in significant increase of the number of newly identified PWBDs reported in China, with over 16,000 new PWBDs reported in their national registry during 2021-2025.

INDONESIA Improving diagnostic capacity remained a key priority throughout the past 5 years of PACT Program in Indonesia, including capacity-building, outreach and identification activities and improved data collection. A national committee was established in 2025 tasked to develop a new web-based registry in Indonesia, with the new registry currently in testing phase. Overall, diagnostic capacity has improved significantly across the country, with 11 provinces now able to conduct routine factor assays (as compared to 8 before the start of PACT program). Furthermore,

genetic testing is now available in the main HTC in Jakarta. Overall, 1,465 new PWBDs were reported in Indonesia during 2022-2025.

KENYA Kenya Hemophilia Association in collaboration with local healthcare authorities continued to implement its outreach activities throughout the country, with over 250 community health assistants from five counties receiving basic training last year on identification and management of bleeding disorders. An educational session was also held for traditional circumcisers from rural areas to help in identification and referral of potential cases, as well as to introduce safe circumcision practices.

MEXICO A laboratory diagnosis workshop was conducted for over 20 laboratory specialists in Mexico to improve coagulation testing, inhibitor detection and interpretation of tests. Such trainings—along with outreach activities and a large-scale national awareness campaign implemented around the World Hemophilia Day resulted in increase in identification and diagnosis. These efforts have contributed to identification of 169 new PWBDs in 2025, with the national registry of people with coagulopathies currently including 7,149 individuals.

SENEGAL PACT program initiatives in 2025 largely focused on outreach and educational activities, including educational and awareness sessions for frontline doctors and medical and dental students, home visits and follow-up referrals of potential cases for confirmatory diagnosis, national public awareness campaign through local and national radio channels among others. In addition, collaboration was established with Senegal's National Association of Midwives that resulted in joint educational workshops for nurses and midwives from Dakar and several provinces.

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

PACT Program's education and capacity-building initiatives aimed to increase equitable access to diagnosis, treatment, and care at the national and global levels, and included its flagship PACT Advocacy Academy, as well as support for series of capacity building and educational activities in 20 PACT participating countries.

"Being on one platform with participants from different countries enriched my perspective and gave me practical ideas I could adapt locally."

—Najmul Alam, President of the Hemophilia Society of Bangladesh.

The PACT Advocacy Academy

In 2025, the fourth PACT Advocacy Academy cohort graduated the course —made up of 21 participants. 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 were offered in English, Spanish and French languages and 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. In addition to attending the live interactive sessions and completing self-directed learning modules on a dedicated online platform, the participants developed their own real-life advocacy projects and received guidance from course faculty, and were matched with mentors from advocacy and bleeding disorders experts.

Overall, during 2021-2025 years, four cohorts completed the course, with 93 graduates from 46 countries from all regions of the world. In a post 12-month evaluation of the course, 77% of the respondents stated having implemented their advocacy projects, and 70% increasing government collaboration.

"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 Suwantaraj, WFH Board Member and Thai Hemophilia Foundation.

Global reach of the PACT Advocacy Academy 2022 to 2025 cohorts



Yobe State HTC opening, Nigeria

In-country trainings

Numerous training and educational activities were conducted locally in PACT countries to enhance NMOs organizational capacities, raise awareness among NMO members, PWBDs and their families on bleeding disorders, and to motivate and empower the community to advocate for improved diagnosis, care and treatment for all. In parallel to this, various targeted training sessions were organized to enhance the knowledge and skills of healthcare professionals in the clinical management of bleeding disorders. A number of these educational activities and capacity building workshops organized in various PACT participating countries are highlighted below.

CHINA – In October 2025, the Hemophilia Treatment Centres Cooperative Network of China, in collaboration with the WFH, organized three national workshops on clinical management of bleeding disorders, specifically for pediatricians, physiotherapists, rehabilitation specialists, and nurses from all over the country to improve comprehensive care for people with hemophilia and other bleeding disorders. It is notable also that the national nurses workshop focused on management of hemophilia among nurses in most resource-constrained regions, as well as on management of females with hemophilia.

BANGLADESH – national workshop on musculoskeletal care of bleeding disorders was organized in October 2025 for 40 hematologists, orthopedists and physiotherapists in Bangladesh, resulting in improved knowledge and skills on managing MSK complications and improved multidisciplinary care for PWBDs.

COSTA RICA – in November 2025, a national symposium on Comprehensive case was organized for healthcare providers, patients and families to continue strengthening care planning and multidisciplinary care for bleeding disorders in the country.



WGBDs workshop, Egypt



National Congress, Mexico

EGYPT – Educational workshops were organized in September 2025 for healthcare professionals and patients and families on diagnosis and management of women and girls with bleeding disorders. ESH also established collaboration with Cairo and Ain Shams universities resulting in creation of a joint WGBD committee and enhanced advocacy and awareness on diagnosis and clinical management of women and girls.

INDIA – in 2025 Hemophilia Federation India conducted two workshops for their Youth and Women’s group members, to enhance engagement and develop practical skills in project proposal writing, social media and communications and use of AI tools. This is part of the overall strategy of NMOs leadership development and succession planning.

INDONESIA – A two-day national workshop was organized for 20 physiatrists from different regions of the country, enhancing their skills in MSK care, use of ultrasound and assessment tools, such as HJHS and FISH.

MEXICO - The 2025 National Hemophilia Congress brought together over 450 attendees, including approximately 90 healthcare professionals. The National Congress scientific program covered current developments in bleeding disorders care, including new treatments and current therapeutic approaches. Practical workshops also included self/infusion and MSK assessments.

NIGERIA – A synovectomy workshop was organized at Enugu HTC in April 2025, which resulted in improved knowledge of local HCPs in chemical synovectomy and development of clinical recommendations and procedural checklist for future synovectomies.

PAKISTAN – Several educational activities were carried out by Hemophilia Foundation of Pakistan and its chapters in 2025. This included a dedicated strategic planning workshop for National Women Group of HFP – SHE LEADS to strengthen leadership and advocacy capacities of the group. The workshop’s main outcome was development of a three-year plan for the National Women



National Women Group workshop, Pakistan

Group. As to the healthcare professional training, a national workshop was organized in October for 40 physiotherapists and orthopedic surgeons on managing MSK complications.

UZBEKISTAN – A national conference was organized in May 2025 for 50 hematologists and other clinicians from all over the country. Key topics covered during the conference included existing and novel therapies for hemophilia and VWD and latest developments in clinical management of bleeding disorders.

VIETNAM – Several training workshops for multidisciplinary teams of main and satellite HTC across the country were organized in Vietnam through PACT program in 2025. This included online training workshops for close to 50 healthcare professionals from HTCs held in August 2025 aimed at enhancing multidisciplinary care and overall coordination between the HTCs across the country. In addition, a dedicated two-day in-person workshop

was organized in December for 54 nurses and MSK professionals on clinical management and MSK care for PWBDs.

ZAMBIA – in March 2025 a national Medical Symposium on Bleeding Disorders was organized that brought together healthcare professionals, PWBDs and family members and government authorities and served as a platform for discussion and exchange on effective coordination and care planning in Zambia. In November month a training workshop was organized in Lusaka University Teaching Hospital on chemical synovectomy and use of ultrasound. Increased focus was also placed on raising awareness on diagnosis and care inequities faced by women and girls with bleeding disorders, with a dedicated Inaugural Ruby Resilience Gala Dinner successfully held in December month with participation of the Permanent Secretary of the Gender Division of the government of Zambia.



National conference, Uzbekistan



National workshop for nurses and MSK professionals, Vietnam

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 advocacy to improve access to diagnosis, treatment and care, capacity building and outreach is a key component of the WFH PACT Program. The Program supported in-country evidence-based advocacy initiatives and collaborative engagements with governments and other stakeholders yielding positive results for the bleeding disorders community.

During 2021-2025, Memoranda of Understanding were signed with governments of Bangladesh, Bolivia, Brazil, Egypt, Palestine and Zambia. Setting a formal partnership framework with the national governments through such agreements reinforces government support and long-term commitment to increasing equitable access to diagnosis, treatment and care. Furthermore, 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, investment in procurement of treatment products, care delivery through opening of new HTC's, policy changes and development of national clinical management guidelines in a number of PACT countries.

Out of 20 countries enrolled in the PACT Program:

14

PACT countries have reported increased government investment expanding access to treatment

6

PACT countries included bleeding disorders in national health policy frameworks

9

PACT countries reported increased government investment in care delivery

13

PACT countries have updated or developed new national guidelines

SEVERAL SELECTED COUNTRY-LEVEL OUTCOMES ARE HIGHLIGHTED BELOW:

BANGLADESH – Change in government and temporary provisional government in 2025 caused challenges for continued advocacy and dialogue with healthcare decision-makers in 2025. Regardless of these challenges, two additional HTC's were recognized in remote areas in 2025, marking an important step toward expanding outreach and improving access to hemophilia care. In 2026, national elections will be held in Bangladesh, which will reinstate permanent government creating more favorable conditions for advancing dialogue with relevant government agencies.

BOLIVIA – national hemophilia conference was held in December 2025 with the National Hemophilia Program established under the umbrella of the

Ministry of Health and the first National Hemophilia Care Standards officially adopted.

BRAZIL – consistent advocacy efforts of the WFH, NMOs, healthcare providers and other stakeholders in the country, including formal collaboration framework set by the PACT Memorandum of Understanding with the Federal government of Brazil, the country has been witnessing consistent increase of government investment in sustainable access to treatment in Brazil. Notably, access to factor replacement therapies, as well as non-factor replacement therapies has been increasing steadily during the past several years.

COSTA RICA – Regular dialogue was maintained with Costa Rican Social Security Fund, with several working meetings organized by the NMO and main clinicians



Nigeria Treatment Guidelines Working Group

with healthcare decision-makers to improve care planning, monitoring and coordination in the country.

EGYPT – Ongoing successful advocacy of the Egyptian Hemophilia Society, in close partnership with leading clinicians and the WFH has resulted in expanding access to prophylaxis for people with hemophilia nationwide, with over 3,000 people with hemophilia having now access to regular prophylaxis through both factor and non-factor replacement therapies. Health Insurance Organization now also covers genetic testing for complex cases. Active dialogue is also underway to maintain the achievements and further expand prophylactic treatment to all patients with severe hemophilia with key stakeholders from the Ministry of Health as well as Senate. A policy roundtable meeting we organized in September 2025 with focus on expansion of prophylactic treatment.

INDIA – National Treatment Guidance for Hemophilia was developed and launched at the World Hemophilia Day celebration event in April 2025, representing a significant step forward towards harmonizing

standard of care across India’s various states. HFI in collaboration with the leading clinicians have continued their advocacy and dialogue with state level healthcare decision-makers, including two dedicated workshops for Aluva and Amrita state blood cell officers on best practices and principles of care for bleeding disorders. Such state level initiatives provided an important forum for sharing best practices and successful experiences in setting up state programs and healthcare services for PWBDs across states. Consistent advocacy initiatives of HFI and leading treatment centres have resulted in systematic increase in access to factor and non-factor replacement therapies across majority of states in India, reporting average annual 9% increase in local procurement of treatment products for Hemophilia A and average annual 4% increase in local procurement of treatments for Hemophilia B nationwide during the past three years.

INDONESIA – advocacy to increase access to treatment and improve standard of care across provinces has remained a key priority of PACT



National Medical Symposium on Bleeding Disorders, Zambia

program in Indonesia. Last year, regular dialogue was maintained with the Ministry of Health and National Health Insurance agency with focus on expanding prophylaxis, home treatment and coverage of out-of-pocket expenses for patients. As a result of consistent advocacy with healthcare decision-makers, significant progress has been achieved in these areas, with now 15 out of 38 provinces implementing prophylaxis program, and 13 provinces having introduced home treatment making care more accessible to patients.

NIGERIA – In 2025, significant progress was made to develop national treatment guidelines in collaboration with Hemophilia Foundation of Nigeria, leading clinicians and the Federal Ministry of Health of Nigeria. The guidelines have been finalized and submitted to the Federal Ministry of Health for formal adoption. A new hemophilia treatment centre was established in Yobe state and a training for community health workers. This brings total number of HTC's

from 13 to 18 in Nigeria during the duration of PACT program.

PAKISTAN – Hemophilia Foundation of Pakistan's advocacy in close partnership with chapters and key clinicians has led to tangible improvements in access to treatment in several provinces during recent years, including Sindh and Balochistan, where provincial governments allocated funding to initiate prophylaxis for 40 and 50 children with hemophilia respectively. Free of charge diagnostic tests are offered in two government hospitals in Sindh and Punjab provinces (Children's hospital in Lahore and Abbasi Shaheed Hospital in Karachi). Concerted advocacy efforts are implemented in all main provinces to expand access to diagnosis and treatment in the country.

LOOKING AHEAD

In 2025, the WFH completed implementation of the first five years of the PACT Program. As we are launching the next phase of the program for 2026-2030, we reflect on the significant strides made and tangible results achieved through this global flagship initiative during 2021-2025.

Global Reach: online training and education

We will continue to offer the PACT Advocacy Academy to NMO leaders and advocates from around the world, with a revamped course content launched in 2026 focusing on existing and novel therapies, procurement mechanisms and effective strategies. Participants will also learn how to develop policy briefs.

A new treatment planning tool will be developed by the WFH expert working group as a tool for countries to project treatment needs and plan effectively national procurement.

National Focus

20 countries will be enrolled in PACT program during 2026-2030. These countries include a combination of countries previously enrolled in PACT and new countries, notably: Armenia, Bangladesh, Brazil, Dominican Republic, Egypt, India, Indonesia, Ivory Coast, Kenya, Mexico, Morocco, Nigeria, Pakistan, Paraguay, Senegal, Serbia, Sri Lanka, Thailand, Tunisia, and Zambia. Participating countries will develop five-year national plans including SMART objectives and tailored outreach, educational and advocacy activities.

Regional stakeholder meetings

Annual regional workshops will be organized each year bringing together key stakeholders, including NMO leaders, key clinicians and national government representatives. These meetings will serve as a platform to deliberate and identify effective strategies for sustainable financing and equitable access to safe and effective therapies for bleeding disorders in the regions.

LIST OF WFH 2021-2025 PACT COUNTRIES AND NMOS

PACT Country	NMO	PACT Country	NMO
Argentina	Fundación de la Hemophilia	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	Nigeria	Hemophilia Foundation of Nigeria
China	Hemophilia Treatment Center Collaborative Network of China	Pakistan	Hemophilia Foundation-Pakistan
Costa Rica	Asociación Costarricense de Hemofilia	Palestine	Avenir Foundation
Egypt	Egyptian Society of Hemophilia	Senegal	Association Sénégalaise des Hémophiles
India	Hemophilia Federation India	Uzbekistan	Uzbek Society of Patients with Hemophilia
Indonesia	Indonesia Indonesian Society of Hematology and Blood Transfusion	Vietnam	Vietnam Hemophilia Association
Kenya	Kenya Hemophilia Association	Zambia	Haemophilia Foundation of Zambia



National Treatment Guidance Launch, India

Thank you to the WFH PACT Program partners for their invaluable support in 2025

VISIONARY PARTNER



LEADERSHIP PARTNERS



World Federation of Hemophilia
1184 rue Sainte-Catherine Ouest
Bureau 500
Montréal, Québec H3B 1K1 Canada

Tel.: (514) 875-7944
E-mail: wfh@wfh.org
www.wfh.org

