



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 care provision worldwide. Today, we are proud of the positive impact this program has brought to the global inherited bleeding disorders community.

The program made significant progress in 2024. Notably, the five-year objective of identifying 20,000 new people with bleeding disorders (PWBDs) across 20 PACT countries has already been achieved and exceeded. This milestone reflects the continued momentum and effectiveness of the initiative. Also, the third 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, supports leaders and advocates from WFH national member organizations (NMOs) in building effective advocacy skills.

In addition, the program has fostered stronger dialogue and partnerships with national governments in participating countries, facilitating progress toward improved healthcare 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 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 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.)

We anticipate the next year with optimism as we continue advancing towards the goals of the WFH PACT Program and 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 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 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 subjectmatter 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 meetings to provide a forum conducive to knowledge-sharing.

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

Twenty countries worldwide participate in the WFH PACT Program. Each PACT country develops a national access plan that includes tailored training, and outreach and advocacy activities to increase support from national governments for bleeding disorders programs. The program also maintains a global reach through training and educational activities, as well as the PACT Advocacy Academy.





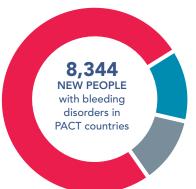
Community Health Volunteers Training, Kenya

2024 WFH PACT PROGRAM – HIGHLIGHTS AND IMPACT STORIES

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

Accurate diagnosis is the first step in accessing treatment and care. Increasing the identification of new PWBDs is one of the main objectives of the WFH PACT Program. As more individuals are identified and included in national 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 20 PACT countries reached 8,344 in 2024.



People with hemophilia: 6,337

von Willebrand disease (VWD): 1,038

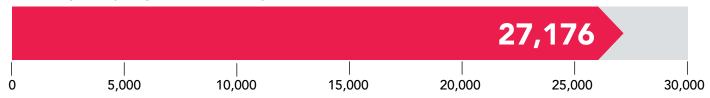
Other bleeding disorders: 969

The WFH PACT program supported a series of national initiatives directed towards increasing identification rates and improving diagnostic capacity in participating countries. These initiatives included laboratory diagnosis workshops, outreach 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.



NMO Chapter Launch and Training in Livingstone, Zambia

Since 2021, **27,176** new people with bleeding disorders have been identified in PACT countries, surpassing the 5-year goal of 20,000 newly identified patients.



ARGENTINA The Argentina Foundation (the WFH NMO) implemented a project focused on increasing identification of women and girls with bleeding disorders (WBGD) and carriers, which resulted in the inclusion of newly diagnosed WGBD in the national registry, with 69 new PWBDs identified last year.

COSTA RICA The national patient registry was updated and improved data collection mechanism put in place to include newly-diagnosed patients on a regular basis into the national registry in Costa Rica. 77 new PWBDs were identified and included in the registry last year.

CHINA The 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.
These efforts along with regular updating of the
national registry have contributed to increased
identification of PWBD in the country, China having
reported 2,611 new PWBDs identified last year.

INDIA A three-day laboratory diagnosis workshop was organized for 16 laboratory technicians and pathologists from seven hemophilia treatment centres (HTCs) in the Northern and Eastern states of India, enhancing their diagnostic capacity for hemophilia and other bleeding disorders. This training—along with outreach efforts and regular updating of the national registry by the NMO—have contributed to the identification of 1,042 new PWBDs in the country last year.

INDONESIA A data collection workshop was organized for over 230 representatives from the Indonesia Hemophilia Society's chapters with the objective of improving data collection and reporting on bleeding

disorders across the country. The capacity to collect quality data is pivotal in expanding national registries. 477 new PWBDs were reported in Indonesia last year.

KENYA Kenya Hemophilia Association in collaboration with local healthcare authorities continued to implement its outreach activities throughout the country, with close to 250 community health workers from seven towns and counties receiving basic training on identification and management of bleeding disorders. Four lab technicians have also been trained in the diagnosis of von Willebrand Disease. The Clinical Practice (CPD) guidelines of the Kenya Medical Laboratory Technicians and Technologists Board (KMLTTB) have been reviewed. These activities have resulted in 185 new PWBDs being identified last year.

MEXICO A laboratory diagnosis workshop was conducted for 14 laboratory specialists in Mexico with a focus on hemophilia diagnostic testing, inhibitor testing and vWD diagnosis. Such training—along with outreach activities carried out by the NMO in several states—have contributed to the identification of 115 new PWBDs last year.

NIGERIA Three educational workshops were organized for 120 community health workers in the Katsina, Kogi and Plateau states of Nigeria with the aim of raising awareness of bleeding disorders, the recognition of bleeding symptoms and the support identification and diagnosis efforts. Seventy new PWBDs were identified in the country last year.

ZAMBIA A national laboratory diagnosis workshop was organized in university teaching hospital in the capital for 18 laboratory specialists from various regions of the country, preceded by a series of outreach activities during World Hemophilia Day, resulting in the identification of 41 new PWBDs.

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 aim to increase equitable access to diagnosis, treatment, and care at the national and global levels.

Virtual trainings

The 2024 PACT virtual training session was held for 106 HCPs and NMO members focusing on the WFH Guidelines for the Management of Hemophilia, including the ongoing updates and value of the living guidelines model, different methods of guideline dissemination and implementation, and PACT country experiences of developing and implementing national guidelines for the management of hemophilia.



WFH webinar on treatment guidelines

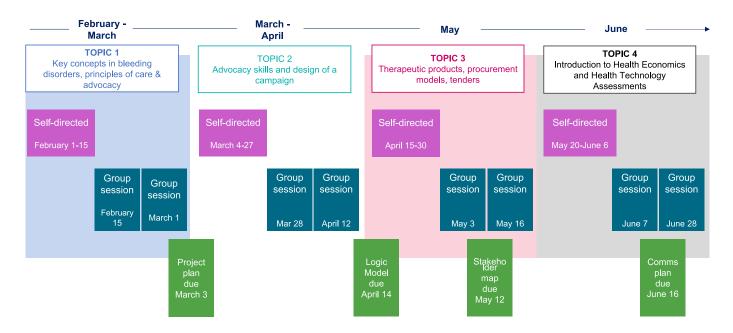
The PACT Advocacy Academy

The third PACT Advocacy Academy cohort—made up of 24 participants from 18 countries—completed their course in 2024. 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.



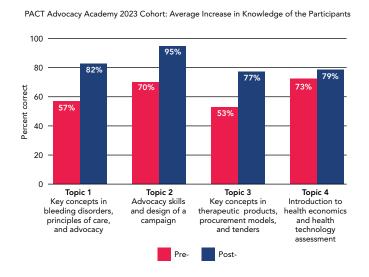
As in 2023, last year, the course was offered in English,

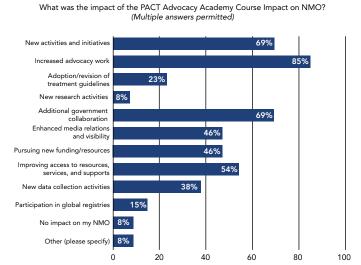
French and Spanish, further expanding the global reach of the PACT Advocacy Academy. In addition to attending the live interactive sessions and completing self-directed learning modules on a dedicated online platform, the participants developed their own real-life advocacy projects and received guidance from course faculty, and were matched with individual mentors from advocacy and bleeding disorders experts.



The 2024 cohort participants demonstrated an increase in knowledge related to all course modules, as highlighted in the pre- and post-session quizzes. Participants 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 2024 cohort evaluation and feedback, we also surveyed the 2023 cohort participants 12 months after graduating from the course to understand what impact the PACT Advocacy Academy had on their advocacy work, and their overall NMO programs and initiatives. According to the findings of this evaluation, 77% of the respondents stated that they implemented their advocacy projects developed as part of the course. 85% of the respondents also reported that their NMOs increased their advocacy work, with 70% launching new activities and initiatives, and 70% increasing government collaboration.





"I feel **more empowered** to engage in advocacy work, thanks to a deeper understanding of the complexities within the bleeding disorders landscape. I've come to realize that advocacy is **not a one-time effort**; it requires continuous engagement with stakeholders through regular updates and follow-ups. This **ongoing interaction** is crucial for maintaining momentum and ensuring long-term success."

-Medhanit Getahun, Ethiopian Hemophilia Society (EHS), Ethiopia, 2023 cohort

"[The course] has enhanced my skills in advocacy and other topics drastically, which will be extremely helpful for my future advocacy efforts. I am grateful to the whole WFH and PACT teams for this amazing course, which will support me in advocacy efforts to realize my objectives of reducing hemophilia-related suffering and enhancing the lives of those people with hemophilia. Thank you."

-Vamshi Durgam, India, 2024 cohort

"The course is indeed very enlightening and empowering, I truly hope it will continue to grow beyond where it currently is, in the future. It is an important course which provides the skills necessary to improve the impact of NMO initiatives and strategies."

— Retselisitsoe Mahlaha, Lesotho, 2024 cohort

"[A significant outcome of my project since completing the course is that] we got all patient with inhibitors on non-replacement therapy... group that worked on this project connected on family level."

-2022 participant, post 1-year evaluation

Global reach of the PACT Advocacy Academy 2022 to 2024 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 on bleeding disorders, and to motivate and empower the community to advocate for improved diagnosis, care and treatment for all. In addition 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 The Hemophilia Treatment Centres Cooperative Network of China, in collaboration with the WFH, organized the 14th national hemophilia conference with over 1,000 healthcare professionals involved in clinical management of bleeding disorders, along with national workshops for pediatricians, physiotherapists, rehabilitation specialists, and nurses from all over the country to improve comprehensive care for people with hemophilia and other bleeding disorders.

PAKISTAN Several educational and capacity-building workshops were conducted in different provinces of Pakistan for healthcare professionals, government officials, patients and their families. These included educational sessions and workshops on multidisciplinary care, specialized services for women and girls with bleeding disorders, a dental screening activity at the School of Dentistry, orthopedic Camp, and more. These educational activities reached 166 healthcare professionals from various disciplines, 180 government officials and 380 PWBDs and their families.



WFH-HTCCNC National Conference, China



National workshop on women and girls with bleeding disorders, Pakistan

EGYPT Educational symposium was organized for multidisciplinary team members on several topics, including standards of care for hemophilia, VWD and other bleeding disorders; the management of musculoskeletal complication; the transition from pediatric to adult care; and WGBD. The NMO leveraged various key national scientific meetings to raise awareness and general knowledge on bleeding disorders among broader groups of healthcare professionals, including dedicated sessions on bleeding disorders at the congresses of the Egyptian Society of Pediatric Hematology & Oncology, Egyptian Society of Hematology and Research, Egyptian Foundation for Rare Diseases, Zagazig University Annual Pediatric Hematology Congress, Upper Egypt Hematology and Oncology Congress, among others. The NMO also organized youth empowerment camp for over 30 youth members to increase youth engagement and expand its volunteer base.



Multidisciplinary Care Symposium, Egypt

INDONESIA The Indonesian Hemophilia Society (IHS) held its seventh National Congress last year, bringing together close to 300 clinicians and multidisciplinary specialists, as well as PWBDs and other IHS volunteers. A dedicated educational workshop was also organized for 49 rehabilitation specialists and physiotherapists from various centres in Indonesia. The IHS also conducted two self-infusion workshops as part of their prophylaxis project.

VIETNAM With the launch of the new national treatment guidelines, the Vietnam Hemophilia Association focused its efforts on supporting the implementation of the guidelines in clinical practice. An educational webinar was organized for clinicians and nurses from all main HTCs around the country on the main recommendations in the guidelines and hemophilia prophylactic treatment, with experts also invited to present experiences from Thailand and Malaysia. In addition, a study visit and educational workshops were organized for physiotherapists and rehabilitation specialists from Vietnam in Malaysia with an emphasis on musculoskeletal care and outcomes-based assessments.



Workshop for physiotherapists from Vietnam HTCs, in Ampang Hospital, Malaysia

A participant of the two-day physiotherapy workshop held at Hemophilia Comprehensive Care Center in Ampang Hospital, Malaysia on December 12 to 13, 2024, Pham Thi Duyen, MD, from Vietnam National Children's Hospital, described the workshop as an excellent opportunity to gain knowledge and updates on hemophilia management from experienced physiotherapists in Malaysia. She found the Hemophilia Joint Health Score (HJHS) theory and practical sessions particularly valuable for assessing patients' joint health and intends to apply the knowledge in her own practice.

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 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 Bolivia and Brazil are two milestone achievements in 2024. Setting a formal partnership framework with the governments through an MoU reinforces government support and long-term commitment to increasing equitable access to diagnosis, treatment and care.

The WFH PACT Program: new MoU signed in Bolivia

In November 2024, the WFH and the Ministry of Health and Sport of Bolivia signed a MoU to implement the WFH PACT Program. The Program aims to improve diagnosis and increase access to treatment and care for people with bleeding disorders in Bolivia. The MoU was signed by Cesar Garrido, WFH President and Marcelo Laura Guarachi, the Vice Minister. During the visit, the WFH also participated in the National Blood Program's Annual Meeting, fostering collaboration with the healthcare professionals and patient advocates, together with the leadership of the Fundacion Nacional De Hemofilia Bolivia (FUNAHEB), the NMO.



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The WFH PACT Program: new MoU signed in Brazil

In November 2024, an MoU was signed for the WFH PACT Program partnership between the WFH and the National Blood Program in Brazil, a federal agency overseeing bleeding disorders care program in the country. The MOU was signed by Cesar Garrido, WFH President and Dra. Joice Aragao de Jesus, the Director of the National Blood Program. The MOU represents a new milestone in a more than two-decade-long collaboration. During this visit, the WFH also participated in the annual meeting organized by the NMO, Brazilian Hemophilia Federation, the Juntos Pela Hemofilia.

Policy changes and increased government investment in treatment and care delivery

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. With the support of the WFH PACT Program, several participating countries have also established working groups and/or initiated formal consultations to facilitate developing national treatment guidelines.

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. This is reflected in steady annual increases in identification and diagnosis rates, a notable increase in budget allocated for procurement of therapeutic products, and the expansion of the network of HTCs in the country.

EGYPT Ongoing successful advocacy of the Egyptian Hemophilia Society, in close partnership with leading clinicians and the WFH has resulted in further expanding access to prophylaxis for pediatric patients nationwide, as well as adult patients covered by the Health Insurance Organization. Active dialogue is underway on expanding prophylactic treatment to all patients with hemophilia with key stakeholders from the Ministry of Health as well as the Senate. Two new hemophilia treatment Centres of Excellence were also established in Ain Shams Pediatric Hospital and El Nile Insurance Hospital.



WFH visit to Argentina

"The longstanding collaboration between the Egyptian Ministry of Health and Population (MoHP), the World Federation of Hemophilia (WFH), and the Egyptian Society of Hemophilia has been instrumental in transforming care for individuals living with bleeding disorders in Egypt. The MOU signed in 2023, and the implementation of the WFH Path to Access to Care and Treatment (PACT) Program in Egypt, helped strengthen national efforts in early diagnosis, access to care and prophylaxis for patients living with bleeding disorders in Egypt —especially for children with severe hemophilia; bringing us closer to achieving universal, equitable care for all individuals with bleeding disorders, where no one is left behind. This collaboration reflects our collective commitment to ensuring that every individual with a bleeding disorder receives comprehensive, equitable, and high-quality care. As we look to the future, we remain deeply committed to expanding this partnership by integrating global best practices, investing in capacitybuilding for healthcare professionals, and scaling access to innovative therapies. Together, we are building a sustainable, patient-centered model of care that leaves no one behind."

Hatem Amer, Associate Minister of Health
 Population for International Relations,
 Ministry of Health & Population – Egypt

NIGERIA New National Policy on Non-Communicable Diseases (NCDs) was launched in 2024, highlighting bleeding disorders as one of the priority areas. The Federal Ministry of Health also increased the number of dedicated State Desk Officers from five to eight. The network of HTCs was also expanded in Nigeria last year, with two new HTCs established in Katsina and Plateau states respectively.

PAKISTAN As a result of the successful advocacy efforts of the Hemophilia Foundation of Pakistan with both federal and provincial healthcare decision-makers, the provincial government allocated funding for the procurement of therapeutic products, particularly non-replacement therapies, for PWH in Sinh and Balochistan. These advocacy efforts laid the foundation for establishing HTCs within government hospitals, aiming to integrate bleeding disorder care into public health services. Satellite HTCs were established in Multan, in Children Hospital in Lahore, in Civil Hospital in Shanghar, in Sindh and Abbasi Shaheed Hospital in Karachi, Sindh in addition to PIMS bringing treatment and care closer to patients in underserved regions.

SENEGAL Following the foundation laid by inclusion of hemophilia as one of the main priorities in the governments national strategic plan on non-communicable diseases in 2023, and as an outcome of ongoing advocacy and strengthened collaboration between the Association Sénégalaise des Hémophiles and the Ministry of Health, the Senegal government restarted procurement of therapeutic products for PWH in 2024 after several years of interruption.

UZBEKISTAN Updated national guidelines for management of hemophilia were developed and adopted in 2024 in an effort to harmonize the national clinical guidelines with the WFH Guidelines for Management of Hemophilia, 3rd edition. The NMO also successfully advocated with the government to change their registration status to that of a national association, allowing them to expand their outreach and educational activities to the regions of Uzbekistan.

ZAMBIA Building on the commitments made by the Ministry of Health of Zambia through WFH PACT Program MoU in 2023 and as a result of ongoing advocacy by the Hemophilia Foundation of Zambia, the government continued to allocate funding for procurement of therapeutic products for treatment of PWH.



Nigeria PACT NCD Policy Launch - August 22, 2024

LOOKING AHEAD

2025 marks the last year of the WFH PACT Program's 5-year plan. We will accelerate our efforts to meet the PACT program objectives by the end of year 5.

Online training and education

We will continue to offer the PACT Advocacy academy course in English, French and Spanish in 2025. A review of the outcomes of the advocacy campaigns of the participants of the 2024 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.

National access plans

Participating PACT countries will continue implementing their National Access Plans including tailored outreach, educational and advocacy activities to make progress towards their five-year targets. The political instabilities in Nicaragua and the ongoing Palestine conflict have had an impact on the implementation of planned in-country initiatives. The WFH remains committed to continue supporting bleeding disorders communities in these countries. 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 4th WFH Global Policy and Access Summit planned to take place from July 10 to 11, 2025. This session will highlight the impact of the WFH PACT Program, and showcase the accomplishments of participating NMOs and PACT Advocacy Academy graduates, in particular their advocacy projects, outcomes and lessons learned.

LIST OF 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

^{*} PACT Program activities in Palestine have been put on hold due to the political situation.



Zambia PACT patient training and NMO chapter launch on August 20 and 21, 2024, in Livingstone

Thank you to the WFH PACT Program partners for their invaluable support in 2024

VISIONARY PARTNER



LEADERSHIP PARTNERS





