



WFH

PACT
PROGRAM

2022

IMPACT
REPORT



WFH

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



MESSAGE FROM THE WFH (WORLD FEDERATION OF HEMOPHILIA)

Dear friends,

The World Federation of Hemophilia's (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 unites 147 National Member Organizations (NMOs), healthcare providers (HCPs), partner organizations and agencies and the global bleeding disorders community at large around this shared vision. The WFH provides NMOs and HCPs with the knowledge and tools they need to identify, support and treat people living with bleeding disorders in their communities while promoting global advocacy and collaboration to achieve our common goals.

Guided by its vision of **Treatment for All**, the WFH launched the Path to Access to Care and Treatment (PACT) Program in 2021. Today, as we are at the midpoint of this five-year global initiative, we look back and reflect on the progress we have made so far, and lessons learned. In two years, we have contributed to a notable increase in identification of new PWBD globally. We have launched PACT Advocacy Academy – an online course for NMO leaders and advocates developed jointly with the New York University (NYU) Robert F. Wagner Graduate School of Public Service and a working group of experts from bleeding disorders community. We have also made significant strides in developing dialogue and partnerships with national governments in many PACT countries to deliver better care.

This impact report highlights the progress made through joint efforts of the WFH and all its key partners and national stakeholders, and shares experiences from program participants. This progress has been possible thanks to the commitment and close collaboration of all our partners, including WFH NMOs, healthcare providers, collaborating government institutions and industry partners. We would also like to thank the WFH staff for their professionalism and dedication.

We are grateful to our PACT Advocacy Academy partners and expert working members:

- 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 look ahead optimistically to coming years, as we continue to move forward towards the PACT program objectives of improving outreach and diagnosis and increasing access to sustainable care for people living with bleeding disorders around the globe.



Cesar Garrido
President



Alain Baumann
CEO



Salome Mekhuzla
Director, Global
Development

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

The 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 people with bleeding disorders 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:



ONLINE TRAINING AND EDUCATION

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

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



NATIONAL ACCESS PLANS

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

Mentorship from subject-matter experts for NMOs in target countries support the implementation of national access plans as well as guidance to PACT Advocacy Academy participants.

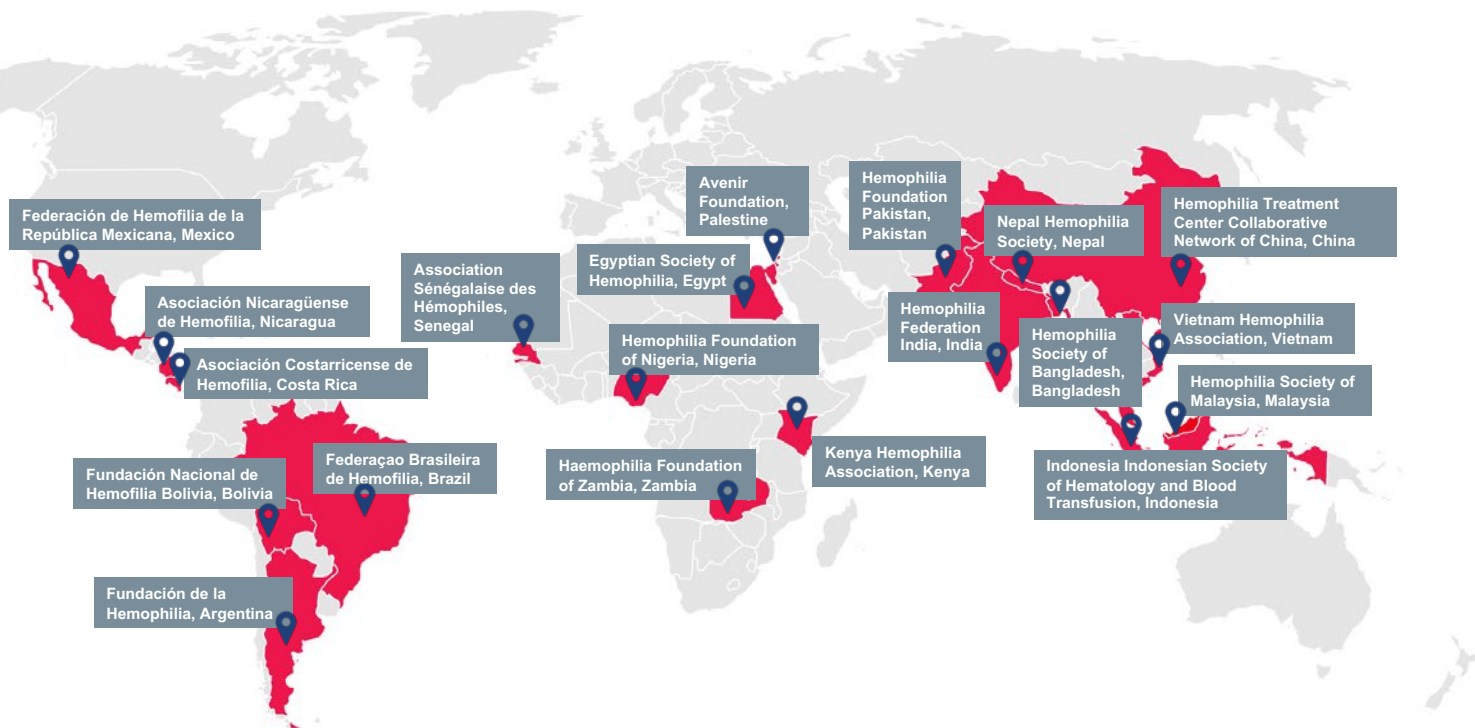


GLOBAL AND REGIONAL MEETINGS

Global and regional training and meetings make it possible to share best practices on evidence-based advocacy between community leaders and promote dialogue and engagement between the main stakeholders.

WHERE WE WORK

Twenty countries worldwide participate in the PACT Program. As part of the program, each PACT country develops a National Access Plan that includes personalized training, 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.



ZAMBIA First national bleeding disorders conference

2022 PACT PROGRAM — STORIES OF PROGRESS

1 IDENTIFY 20,000 new people with rare bleeding disorders in the 20 targeted countries.

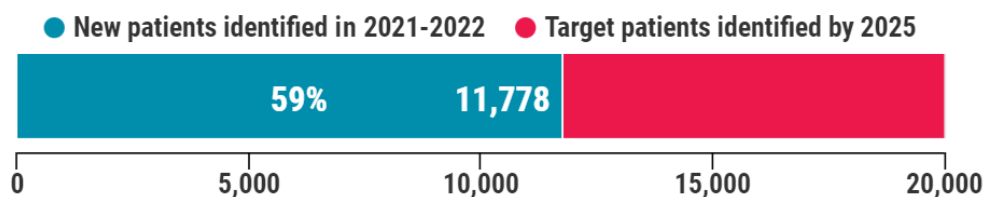
Accurate diagnosis is the first step in accessing treatment. This is why identifying PWBDs is one of the priorities of the PACT Program. As more individuals are identified and included in patient registries, this increases the patient population and amplifies patient voices, demonstrating the need for sustainable and comprehensive care and treatment.

The number of new PWBDs identified in PACT countries in 2022 reached 7,337.



PACT initiatives, such as laboratory diagnosis workshops, primary healthcare workers education, outreach activities, the creation of local online data collection tools, and the expansion of the World Bleeding Disorders Registry (WBDR) platform usage, all helped to increase the diagnosis of new cases in 2022.

In Bangladesh, a 24/7 call center was established to help patients, families, and the public access information about bleeding disorders. A mobile application to increase patient identification was developed and launched in Kenya, and series of training on its use were conducted among medical personnel, patients, parents, and women with bleeding disorders. In Costa Rica, a registry campaign was launched to help increase the identification of new patients with bleeding disorders.





KENYA Launch of a new mobile app for patient identification and training of HCPs on its use



NIGERIA In June 2022, 36 community healthcare workers participated in an outreach and education activity in the State of Anambra. The activity provided basic training on bleeding disorders and patient identification. This introductory training allowed the participating community healthcare workers to swiftly identify 11 new patients.

"The PACT Program helps us identify new patients in the country. After seeing the numbers of diagnosed PWBDs, our government expressed willingness to begin purchasing treatment products. We are now in the preliminary stages of discussion to pursue this endeavor with our government."

Megan Buckie Adediran,
Hemophilia Foundation of
Nigeria, Nigeria

2022 PACT PROGRAM — STORIES OF PROGRESS

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 PACT Program's education and capacity-building components help to increase equitable access to diagnosis, treatment, and care at the national and global levels.

Virtual trainings

The 2022 PACT virtual training sessions on comprehensive care provided HCPs and NMO members with theoretical and technical knowledge in delivering comprehensive care and using data to monitor and improve clinical practice and health outcomes.

Online training sessions for HCPs

A two-part training session on delivering comprehensive care was attended by 134 HCPs worldwide. This training equipped participants with practical tools and information on setting up an HTC, expanding comprehensive care services, and improving clinical management and health outcomes of PWBDs in their centres.

Workshop on data collection, with a focus on the *WFH Annual Global Survey*

Thirty-eight participants from PACT countries attended a workshop on enhancing data collection and improving data quality. The workshop also served as an opportunity to learn more about the WFH Annual Global Survey (AGS) and how to maximize the utility of data to support advocacy and outreach initiatives at the national level.

PACT Comprehensive Care **WEBINARS**

WEBINAR 1

Delivering comprehensive care:
key services and roles

FRIDAY, JUNE 3 8:00–9:30am EDT

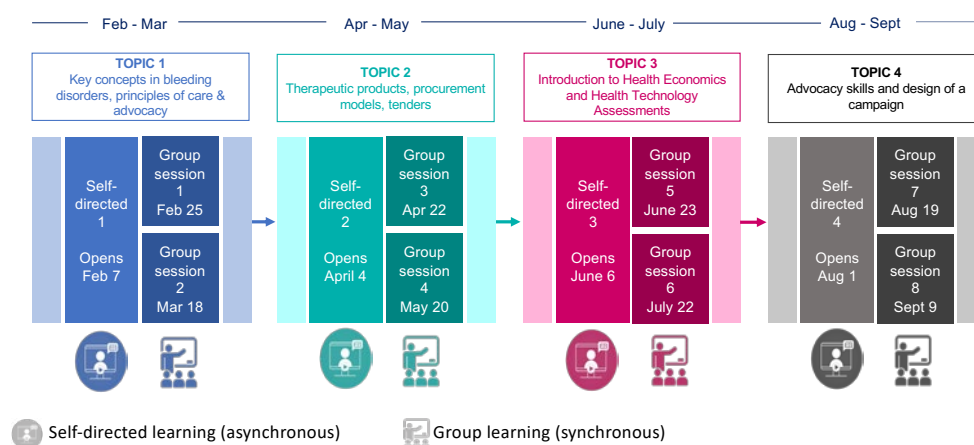


English with
simultaneous
interpretation into
French and Spanish

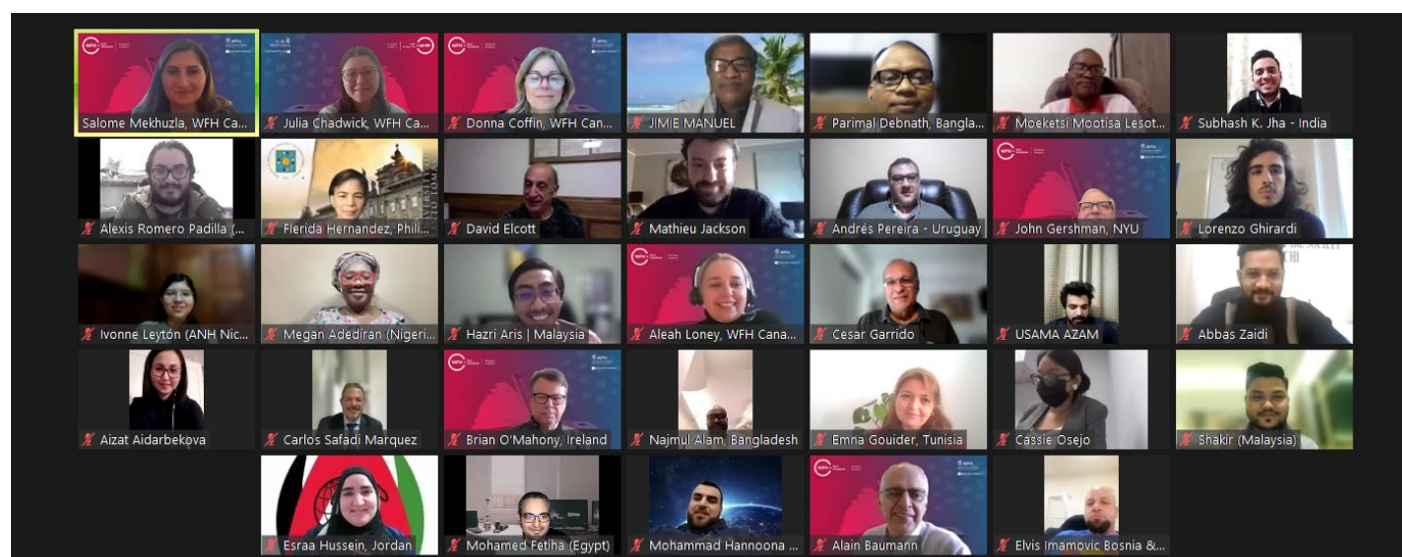


The PACT Advocacy Academy

The first PACT Advocacy Academy cohort was launched in January 2022. For eight months, the participants completed the four main learning modules created by the WFH in collaboration with the New York University Robert F. Wagner Graduate School of Public Service and an expert working group. These modules covered key concepts in bleeding disorders, principles of care, advocacy skills, design of a campaign, introduction to health economics and health technology assessment, and key concepts in therapeutic products, procurement models, and tenders.

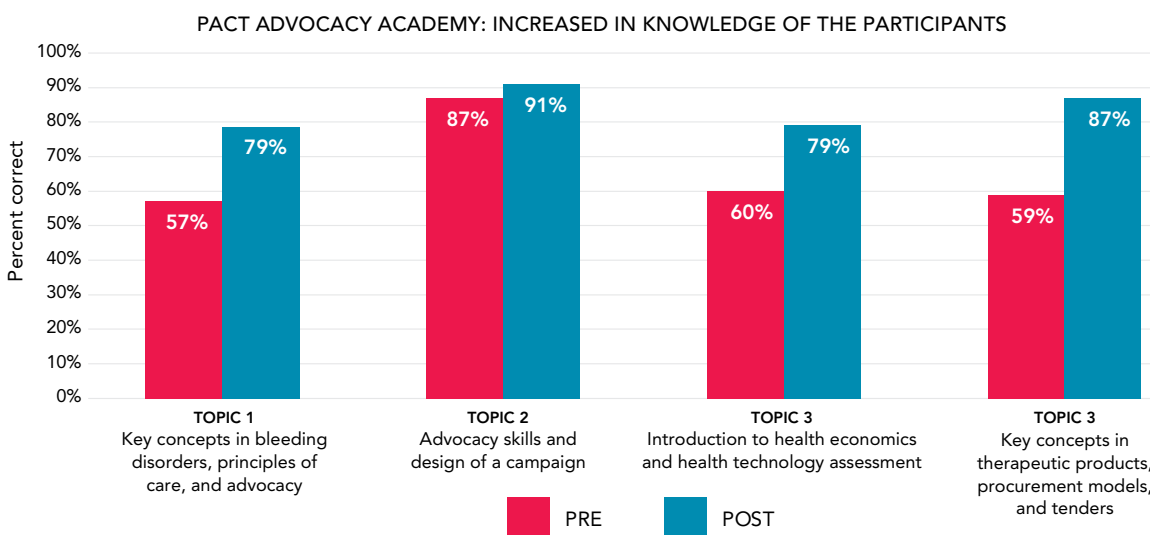


Aside from attending the live interactive sessions and completing self-directed online learning modules, the participants were required to build their own real-life advocacy project. The course brought together a pool of advocacy and bleeding disorders experts to mentor the participants in their advocacy project planning. The 23 graduates produced plans for national advocacy projects that are now being rolled out by their NMOs.



2022 PACT PROGRAM — STORIES OF PROGRESS

Participants of the 2022 cohort expressed favourable feedback on the usefulness of the course and the effective guidance from their instructors, mentors, and fellow participants.



Participant feedback

"I was happy to share my learnings from the PACT Advocacy Academy with the Hemophilia Philippines Foundation (HAPLOS) ... my team will now put into practice the concepts and skills I have learned to advance our lobbying efforts with the Philippine Health Insurance Corporation (PhilHealth), local governments, and the National Institute of Health. The program helped me and my organization, to refocus and reorganize our initiatives for the Philippine hemophilia community."

Flerida Hernandez, Hemophilia Philippines (HAPLOS Community) Foundation, Inc, Philippines

"The exchange of experiences with my classmates was fundamental to seeing different realities and learning from each other."

Juan Andrés Pereira de Souza, Asociación de Hemofilia del Uruguay, Uruguay

"I have gained skills from the PACT Advocacy Academy, and through the mentorship program, I have developed a comprehensive and patient-based approach to program intervention."

Agnes Kisakye, Haemophilia Foundation of Uganda, Uganda

In-country trainings

The 20 PACT countries conducted various in-country training activities to increase awareness and technical capacities and motivate community members to implement new initiatives that advocate for better care.

EGYPT There was a marked improvement in the competency and skills of participants who joined the two-day nurses training in Egypt organized by the WFH in partnership with the World Health Organization (WHO) Egypt Country office. The activity helped to identify leaders to guide the nursing community and fostered collaboration between nurses from 12 HTC's in and outside Cairo.

A workshop launching the national treatment guidelines in Egypt provided a scientific platform to develop principles of care and standardize the clinical management of bleeding disorders in the country. This workshop provided a space for knowledge-sharing on international standards and how they can best be adapted to the local context.

INDONESIA The PACT virtual workshop on data collection and registries provided participants with knowledge and skills for data collection and analysis, as well as the opportunity to engage with local and international experts and government agencies.

PALESTINE The NMO organized virtual and in-person physiotherapy workshops with clinical case presentations and consultations on the appropriate treatment plans in the country. These workshops also targeted musculoskeletal professionals who previously were not involved in hemophilia care and provided them with introduction to bleeding disorders and MSK assessment tools. The trained physiotherapists now apply these tools in managing PWH in their clinics.

“It’s a great experience to participate in such a meeting to discuss the establishment of a national hemophilia nurses core competency framework. The WFH October 2022 training event was very productive and constructive. The interactive session was particularly valuable – allowing nurses to have a voice and facilitating dialogue between participants to not only address challenges but also propose appropriate interventions.”

Mohamed M. Abogad, MD,
Laboratory and Blood Safety Officer,
WHO Egypt



EGYPT WFH-WHO Nurses training



MALAYSIA NMO Leadership workshop

2022 PACT PROGRAM — STORIES OF PROGRESS

NMO capacity development

Strengthening the organizational capacities of the WFH NMOs is one of the priorities of the PACT Program. The NMOs in Bangladesh, Egypt, India, Palestine, Costa Rica, Mexico and Senegal underwent capacity development self-assessments that have resulted in specific action plans addressing various organizational development components and processes. In Senegal, this effort contributed to establishing the key strategic documents of the NMO.

Mentorship support for NMOs participating in PACT Program

As part of the PACT program, participating NMOs can receive advisory support from bleeding disorders and advocacy mentors. In 2022, Dunia Castillo, MD (Cuba) mentored the NMO in Nicaragua. This mentorship provided guidance on improving care delivery and developing a patient registry in the country. A network of centres is being developed to provide primary care to patients living far from the capital city of Managua. The WFH collaborated with the NMO's new executive board to strengthen the NMO's organizational capacities.



INDIA NMO capacity assessment workshop



NICARAGUA NMO planning meeting with the PACT Program mentor

Mentorship opportunities will continue to be offered to other PACT countries in 2023.

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

Governments and other institutions play a critical role in improving access to sustainable treatment and comprehensive care for patients with bleeding disorders. The PACT Program supports in-country evidence-based advocacy initiatives and collaborative engagements with the government and other stakeholders. This approach continues to yield positive results for the bleeding disorders community.

Policy changes

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

BANGLADESH The government's continued support led to the inclusion of hemophilia in the 2nd Operation Plan of Noncommunicable Disease Control, with specific objectives set for the identification of new PWBDs and the dissemination of information about bleeding disorders.

PALESTINE The Ministry of Health of Palestine formally recognized hemophilia as a priority and has been collaborating closely with the NMO in implementing priorities set in the PACT Program Memorandum of Understanding signed between the Ministry of Health and the WFH in June 2022.

NIGERIA The Federal Ministry of Health of Nigeria approved the inclusion of clotting factor concentrates into the national Essential Drugs List. This accelerates the PACT campaign for the government to initiate the procurement of treatment products for PWBD in 2023.

ZAMBIA Hemophilia and other bleeding disorders are now fully integrated into the Noncommunicable Diseases policy and strategic plan of the Ministry of Health.

BOLIVIA The Ministry of Health care system included laboratory diagnosis as a free service for PWBDs, which will immensely facilitate the identification of new patients and the ongoing management of existing patients. Home to the majority of PWBDs in the country, the state of Santa Cruz approved a policy resolution to secure procurement of therapeutic products for the management of PWBDs and assure the prophylactic treatment for 50% of PWBDs.



2022 PACT PROGRAM — STORIES OF PROGRESS

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 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.

MEXICO The National Health Council (NHC) published treatment protocols for people not covered via the social security system. In the consultation process, the local NMO and the WFH successfully advocated for the recognition of comprehensive care as the best model for hemophilia care and inclusion of care for adults. The NHC adopted these statements in its treatment protocols.

BOLIVIA A working group was created to develop the national treatment guidelines based on the 3rd edition of the WFH Guidelines for the Management of Hemophilia.

PAKISTAN The NMO launched a formal consultation process with NMO representatives, HCPs and provincial government officials to finalize the Pakistani National Treatment Guidelines.

Government investment in treatment and care delivery for bleeding disorders

Several PACT countries, including Bangladesh, Bolivia, Egypt and Pakistan, reported increased government provision of therapeutic products for the treatment of bleeding disorders in 2022. In addition to increasing access to therapies, Bolivia continued to provide home treatment for PWBDs, which was initially introduced only as a temporary measure during the peak of the pandemic. Based on the recommendations of the NMO and the WFH, the Ministry of Health in Palestine agreed to digitize patient ID cards to facilitate the identification of people with bleeding disorders (especially in hospital emergency wards) and enable timely access to treatment. Ongoing discussions and an awareness-raising project for government health officials in Nepal increased awareness on the need to improve access to care for PWBDs. In May 2022, the Nepal Parliament publicly declared its plans to provide free treatment for PWBDs.

The consistent advocacy and close engagement in Karachi, Pakistan strengthened the NMO partnership with the Sindh provincial government. In 2022, the provincial government awarded a grant to the Hemophilia Welfare Society Karachi (NMO chapter in Pakistan) to support their activities.

Bangladesh and Pakistan also made strides in establishing new HTC. In Pakistan, a satellite HTC in Multan was opened for primary hemophilia treatment and its staff was trained on the management of PWBDs. In Bangladesh, patients from Khulna and Barishal can now receive care closer to their homes as two new HTCs were established under the auspices of the Medicine and Pediatric Departments.

“Thanks to the PACT Program’s contribution to establishing HTCs in Bangladesh, patients from Khulna and Barishal are receiving better medical attention and care. With the support of these HTCs, our request for government investment for treatment products is also strengthened.”

Mohammad Nurul Islam,
Hemophilia Society of
Bangladesh, Bangladesh

Collaborations with national governments and other institutions

Forging collaboration between the NMOs, country partners, government agencies and other institutions in capacity building and outreach is a key element of the PACT Program.

BOLIVIA The National Blood Program under the auspices of the Ministry of Health and the NMO conducted a medical training attended by 150 HCPs. This led to the setting up of a multidisciplinary care team in the country's five major regions to decentralize care delivery and expand access to care in the regions.

EGYPT A partnership between the WFH and the WHO country office led to a joint national nurses training workshop.

INDIA The NMO partnered with the National Health Mission Jharkhand to organize a state-level educational activity for enhancing medical expertise in hemophilia. Furthermore, the NMO, in collaboration with the Indian Council of Medical Research, the National Institute of Imuno-Haematology and KEM hospital, organized a laboratory diagnosis training for the North-Eastern states of India. Twenty-two pathologists and lab technicians from nine centres in eight states participated in the training.

KENYA In 2023, the Nairobi City Council and the NMO rolled out a training of trainers on using the patient identification mobile application dedicated to the Community Health Volunteer (CHV) supervisors in 2023. The supervisors will train up to 7,400 CHVs on how to use the application.

SENEGAL The Regional Ministry of Health staff conducted educational activities in the four largest regions of the country. These activities increased the knowledge and skills of 95 patients and parents in managing hemophilia.



NEPAL Meeting with the Minister of Health

“At WHO Egypt we value our engagement and collaboration with the WFH and appreciate the initiative they took to reach to out to us towards quality training for nurses in Egypt. The focus on the nurse's track is of paramount importance to WHO—not only because they are the backbone of any health system but also because WHO advocates for improving nurses' competencies to deliver care to all with no distinction. In this vein, raising the capacity of specialized hemophilia nurses is critical.”

Na'eema Al-Gaseer, MD, WHO Representative in Egypt & Head of Mission

2022 PACT PROGRAM — STORIES OF PROGRESS

Establishing formal collaboration with national governments

The signing of a Memorandum of Understanding (MoU) between the WFH and the governments of Palestine and Zambia are two milestone achievements. Setting a formal partnership framework with the governments through an MoU galvanizes government support and long-lasting commitment to achieving the PACT objectives.

The WFH PACT Program: new Memorandum of Understanding signed in Palestine

The WFH and the Palestinian Ministry of Health signed a 5-year MoU on June 5, 2022, to implement the WFH PACT Program. The Palestine PACT program will be jointly managed by the Palestinian Ministry of Health and The Palestine Avenir for Childhood Foundation Hemophilia Committee with the full support of the WFH. This MoU will ensure that more PWBDs in Palestine can reliably access safe treatment and care, regardless of their type of bleeding disorder or gender.

The MoU signed in Palestine lays the foundation for implementing the PACT Program over the next four years. This includes strengthening the Palestinian Ministry of Health National Hemophilia Care Program and forging a consensus around introducing standardized treatment guidelines. The efforts will lead to early and accurate diagnosis, ensure equitable access to care and treatment, and improve the quality of life for PWBDs. The program will also address the need for relevant education and support programs in both the West Bank and the Gaza Strip.



PALESTINE MoU signing ceremony

LOOKING AHEAD

2023 marks the midpoint of the 5-year plan of the PACT program. Moving forward, efforts will be doubled to achieve the program objectives.

Online training and education

Following the success of the first cohort of the PACT Advocacy Academy which was conducted in English, the course will now be offered in English, French and Spanish languages starting in 2023, thus expanding the global reach of the Advocacy Academy. A review of the outcomes of the advocacy campaigns of the participants of the 2022 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 designing innovative outreach and diagnosis projects.

National Access Plans

All 20 PACT countries will continue implementing their National Access Plans to make progress towards their five-year targets. The WFH will continue to offer mentorship opportunities to support NMOs on specific aspects of the respective national plans.

Global and regional meetings

A PACT program session will be organized during the 3rd WFH Global Policy and Access Summit on July 7, 2023. This session will highlight the PACT program achievements and provide opportunities for participating NMOs and PACT Advocacy Academy graduates to share their advocacy projects, successes and lessons learned. In the fourth quarter, a stakeholders meeting will provide a space for PACT countries to encourage cross-learning and collaboration. NMO leaders, HCPs, government representatives, and other PACT partners from the 20 PACT countries will be invited to attend.

LIST OF PACT COUNTRIES AND NMOs

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

The WFH thanks our PACT Program partners
for their invaluable support in 2022

VISIONARY PARTNER



LEADERSHIP PARTNERS



COLLABORATING PARTNERS



World Federation of Hemophilia
1425 René Lévesque Boulevard West
Suite 1200, Montréal,
Québec H3G 1T7, CANADA

Tel.: (514) 875-7944
Fax: (514) 875-8916
E-mail: wfh@wfh.org
www.wfh.org

