

CLOSE THE GAP

Campaign 2012-2014

Be part of the vision.



CAMPAIGN BULLETIN

December 2013 / No. 5



Twenty-eight WFH NMOs have given or pledged over US\$402,000 to the WFH Close the Gap Campaign.

THANK YOU to all participating NMOs for this extraordinary act of global solidarity.



PARTNERS IN SOLIDARITY AND CAMPAIGN SUCCESS

Association française des hémophiles
Association Libanaise de l'Hémophilie
Association Marocaine des Hémophiles
Belgian Haemophilia Society
Canadian Hemophilia Society
Danish Haemophilia Society
Deutsche Hämophiliegesellschaft (DHG)
Egyptian Society of Hemophilia
Fundación de la Hemofilia (Argentina)
Haemophilia Association of Mauritius
Haemophilia Foundation Australia
Haemophilia Foundation of New Zealand
Haemophilia Foundation of Nigeria
HAPLOS – Hemophilia Association of the Philippines for Love
Hemophilia Society of Malaysia
Irish Haemophilia Society Ltd.
Japan Committee for People with Hemophilia
National Hemophilia Foundation (USA)
Netherlands Haemophilia Society
Norwegian Hemophilia Society
Österreichischen Hämophilie Gesellschaft (Austria)
Slovenské Hemofilické Zdrúsenie (Slovak Republic)
Sociedad Hondureña de Hemofilia
Society for Inherited & Severe Blood Disorders (Trinidad & Tobago)
Swedish Hemophilia Society (FBIS)
Swiss Hemophilia Association
UK Haemophilia Society
Vietnam Hemophilia Association

Like any community, the strength of the World Federation of Hemophilia (WFH) lies with our national member organizations (NMOs) and the vital work we do together to improve care for people with bleeding disorders around the world. WFH NMOs are key partners that represent the interests of people with a bleeding disorder in their country.

As the Close the Gap Campaign continues into 2014, we are especially grateful to WFH NMOs that have gone beyond the national scope of their remarkable work. We wish to highlight these extraordinary contributions to our Close the Gap Campaign.

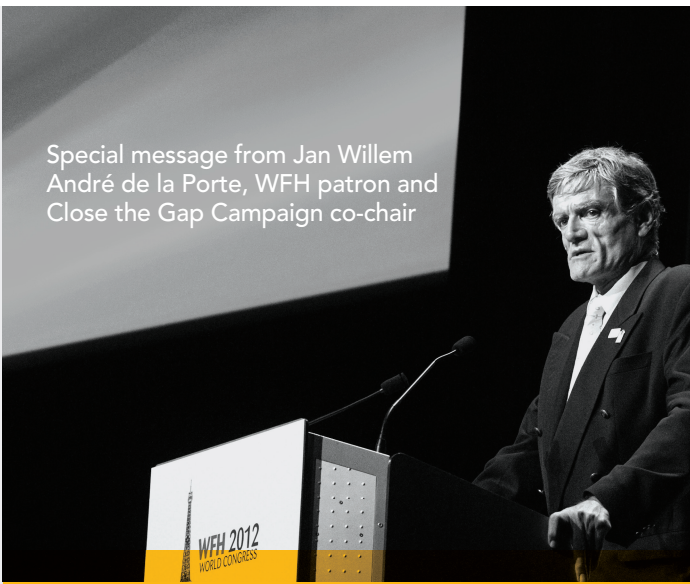
For several years, a small and growing group of WFH NMOs have begun to make donations to the WFH as part of a core commitment for their organizations. Since the launch of the Close the Gap Campaign in 2012, the number of NMOs empowering the WFH mission through these gifts has jumped to 28, nearly a quarter of all accredited WFH NMOs. This speaks to the growth of a philanthropic culture and solidarity among the members of our global family.

NMOs participated in the Campaign in creative and original ways. From grassroots community-wide activities, to multi-year revenue sharing initiatives, each NMO has partnered with the WFH in the manner that best suited their means, resources, and strengths. Some of the ways NMOs partnered with the WFH include: contributing a 1 per cent unrestricted revenues or membership fees; local chapter and treatment centre appeals; World Hemophilia Day activities; as well as collections during their annual general meetings.

The Close the Gap Campaign continues throughout 2014. If your organization would like to partner with the WFH to help fund our next decade of development, please contact your campaign regional co-chair (see page four of this bulletin) or contact Dolly Shinhat-Ross, WFH fund and resource development director, at dshinhat@wfh.org.

We look forward to thanking all NMOs in person at the WFH 2014 World Congress in Melbourne. Visit www.wfh.org/congress to register today.

Special message from Jan Willem André de la Porte, WFH patron and Close the Gap Campaign co-chair



THE PATRON'S CHALLENGE: YOUR DONATION WILL BE TRIPLED

“ I want to inspire WFH friends and supporters to go above and beyond what has already been accomplished in our work toward improving and sustaining care for people with a bleeding disorder.

So I have pledged to provide a 2:1 match of all gifts received from individuals and organization of the bleeding disorders community to the Close the Gap Campaign. To date more than \$150,000 has been given by our community and my match stands at \$300,000.

The challenge continues. I encourage you to take me up on my challenge! ”

Visit www.wfh.org/closethegap to give your gift today.

GIVE TO CLOSE THE GAP IN CARE

\$30 will ship 7,000 international units (IUs) of factor to Kenya to treat acute joint or muscle bleeds

\$125 provides two days of training for a medical team member in his or her country

\$380 will cover the cost to diagnose 10 people with a bleeding disorder in a developing country

\$1,438 will cover the cost to diagnose 50 people with a bleeding disorder in a developing country

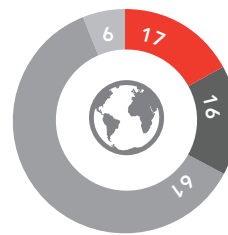
\$4,000 covers the cost of a four-week training program

BE PART OF THE VISION.
WWW.WFH.ORG/CLOSETHEGAP

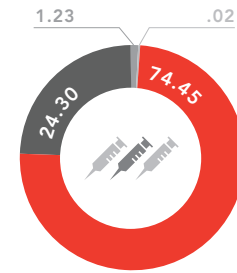
THE GAP IN TREATMENT

For a person with a bleeding disorder, access to proper treatment can make the difference between a life of chronic pain and a future free from disability. Indeed, it can mean the difference between life and death. The highest economically ranked countries account for almost 75 per cent of factor VIII clotting factor concentrate consumption in the world, although they represent only 17 per cent of the world population.

PERCENT OF **WORLD POPULATION** BY ECONOMIC RANK



PERCENT OF **FACTOR VIII CONSUMPTION** BY ECONOMIC RANK

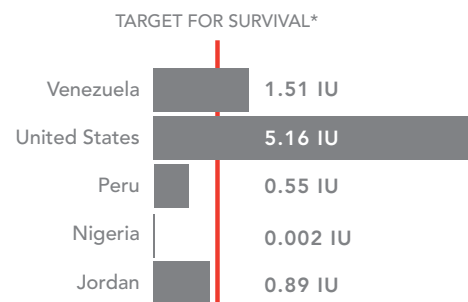


■ Upper ■ Upper Middle ■ Lower Middle ■ Lower

The WFH supports countries with limited or no access to clotting factor concentrates by:

- Training patients and health professionals to manage pain with techniques that do not require treatment products;
- Demonstrating the benefits of factor usage to governments and advocating for improved access; and
- Shipping factor donations to address emergency situations.

FACTOR VIII USAGE PER CAPITA ACROSS THE GLOBE



* One IU of factor FVIII per capita is the minimum target to achieve optimal survival for the hemophilia population. Higher levels are required to preserve joint function or achieve a quality of life equivalent to an individual without hemophilia.

THE WFH HUMANITARIAN AID PROGRAM SAVED THE LIFE OF HIRWA MPANO VIRGILE, OF RWANDA, FOLLOWING AN INTRACRANIAL BLEED THAT REQUIRED IMMEDIATE SURGERY. HOWEVER, THE SURGERY LEFT HIRWA PERMANENTLY BLIND. IF HE HAD RECEIVED ADEQUATE TREATMENT EARLIER, THIS STORY MAY HAVE ENDED DIFFERENTLY. READ MORE ABOUT HIRWA ON PAGE NINE OF THE DECEMBER ISSUE OF *HEMOPHILIA WORLD*.

ADVOCATING FOR IMPROVED ACCESS TO CARE

In 1994, I joined the WFH as the best way to make an international contribution to hemophilia treatment. I was impressed by the organization's programs, governance, fiscal discipline, and succession planning.

In particular, the WFH strategy of creating partnerships between patients, healthcare givers, and government is very important. It is also a working model that organizations around the world can use to improve healthcare in areas outside hemophilia.

I find it very fulfilling to revisit countries such as Lesotho, Botswana, and Tanzania, where they originally had little knowledge of hemophilia. However, after adopting the WFH model, methods of care began to improve and patients' lives were saved as a result.

I will remember the overjoyed mother of a Nigerian boy with hemophilia who told me, "I would like to thank you because my son has not had any bleeds since that time when you came to visit."

"It's all your doing," I replied. "We just facilitate the process." It was a heartwarming encounter and confirmed my involvement with the WFH as very worthwhile.

Sub-Saharan Africa bears a heavy burden of infectious diseases along with treatable, non-infectious maladies such as malnutrition. Such competing demands have created a perception among some health authorities that you can get more for your money rather than making sure people with inherited bleeding disorders receive treatment.

OUR CHALLENGE IS TO PERSUADE REGIONAL HEALTH PROVIDERS, PATIENTS, AND CAREGIVERS THAT THE RIGHTS OF INDIVIDUALS WITH HEMOPHILIA ARE IDENTICAL TO THE RIGHTS OF PEOPLE WITH INFECTIOUS DISEASES. HEALTH RESOURCES SHOULD NOT BE DISTRIBUTED IN A WAY THAT PLACES ONE GROUP AT A DISADVANTAGE. WE NEED TO ADVOCATE AS EFFECTIVELY FOR PEOPLE WITH HEMOPHILIA, AS FOR HIV OR TB PATIENTS.



Johnny Mahlangu (far right) talking to a patient in Ghana.

Following my recent term with the WFH Executive Committee, I will continue to represent the WFH when called upon. It is important to do your bit, move back, and allow others to do the same. This enables an organization to flourish. I am proud to continue my partnership with the WFH as a Close the Gap Campaign regional co-chair for Africa.

DR. JOHNNY MAHLANGU MD
Director, Adult Hemophilia Comprehensive Care Unit,
Johannesburg Hospital
President, South African Society of Hematology
WFH Executive Committee member, 2008-2012
Close the Gap Campaign regional co-chair,
Middle East & Africa

WFH STAFF DEMONSTRATES DEDICATION TO THE CLOSE THE GAP CAMPAIGN

Every day WFH staff sees the challenges faced by the bleeding disorders community not only in one particular region of the world, but globally. Across countries and continents, the struggle for adequate access to care is one that all WFH employees are reminded of on a regular basis.

"We receive letters thanking us for our work and projects every day, but we also hear about the daily challenges and how much is left to be done," said Stephanie Pineda, WFH Program officer - IHTC and IEQAS. WFH staff dedication to our vision of Treatment for All is especially apparent as many have chosen to further partner philanthropically with the WFH beyond their professional roles.

Over half of the WFH staff is participating in the Close the Gap Campaign. Nearly \$5,500 has been pledged to a staff youth fellowship project that will fund a trip for, at least, one young person to attend the WFH 2014 World

Congress in Melbourne, Australia. "We need to have strong support from within the WFH for our campaign to Close the Gap, as much as from the wider community," said Pineda. "This gives us all a chance to be a part of the work the WFH does on the ground, in a real concrete way." In addition to the youth fellowship project, an extra \$3,400 has been pledged or given to help support the WFH's highest priorities.

THANK YOU TO ALL WFH STAFF FOR YOUR UNWAVERING DEDICATION TO THE WFH MISSION, OUR SUCCESS WOULD NOT BE POSSIBLE WITHOUT YOU.



Left: WFH 2012 Global NMO Training youth delegates during a workshop

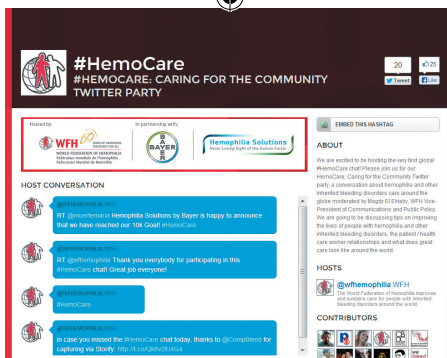
Right: Deon York (middle), WFH chair of the fund and resource development committee, leads a discussion with WFH 2012 Global NMO Training youth delegates



WFH'S FIRST TWITTER PARTY SOARS TO SUCCESS

The WFH was very excited to hold its first Twitter Party, #HemoCare: Caring for the Community, in early October. Hosted by the WFH, in partnership with Hemophilia Solutions by Bayer, the Twitter Party was moderated by Magdy El Ekiaby, MD, WFH vice-president of communications and public policy and Close the Gap Campaign regional co-chair.

In addition to providing a platform to discuss hemophilia care around the world, this unique global chat raised awareness about the WFH International Hemophilia Training Centre (IHTC) Fellowship Program. This program gives health care professionals from developing countries training in the diagnosis and management of hemophilia and other inherited bleeding disorders. In addition, an outstanding US\$10,000 was raised for the Close the Gap Campaign, thanks to Bayer contribution of US\$1,000 for every 50 RSVPs to the party, as well as an additional US\$1,000 for every 50 tweets referencing #HemoCare during the chat.



Support and participation came from across the globe, with 42 cities joining the conversation. We would like to give a special thank you to Close the Gap Campaign regional co-chair for the Americas, Martha Monteros and the Mexican Federation of Hemophilia, for translating the Twitter Party questions into Spanish. Their assistance helped increase exposure to Central and Latin American countries and generated over 125 tweets in Spanish. ¡Gracias!

The WFH is dedicated to reaching our global community across different communications platforms. Read more on page 10 in the December issue of *Hemophilia World* to discover how the WFH has expanded its use of new technologies and social media to increase interaction with our global community.

THE JOURNEY TOWARDS TREATMENT FOR ALL: WFH 50TH ANNIVERSARY VIDEO SERIES

The 50th anniversary Close the Gap video series highlights key moments, programs, and people in the 50 year history of the WFH. To view videos in the series, please visit www.wfh.org/50.

Close the Gap

Highlights the differences between children who have received care for their bleeding disorder and those who suffer without care.

The Winning Coalition

Assad Haffar, WFH deputy director of programs, narrates this film, recounting the establishment of a national care system for people with bleeding disorders in Senegal.

Changing Lives Through Twinning

Yuri Zhulyov and Paula Bolton-Maggs, MD, reflect on their involvement with the WFH Twinning Program.

Progressing Care Globally

Learn how China experienced rapid improvements in care after participating in the WFH's GAP Program.

Volunteering Brings Change

Dedicated to the remarkable people who donate generously their time, expertise, and energy to the WFH and its national member organizations.

Empowering Patients

Antonia was determined not to let her son, diagnosed with hemophilia follow the same fate as three of his cousins who died from complications due to hemophilia.

The Journey Begins

Outlines how Frank Schnabel's personal experiences as a hemophilia patient inspired him to found the WFH in 1963, with the goal to improve care for the worldwide bleeding disorders community.

Bridging the Gap in Treatment

Narrator Alison Street, MD, (WFH vice-president medical, 2008-2012), discusses how the Humanitarian Aid Program reaches developing countries in need.

Leaders in Training

Since the IHTC program was launched in 1972, over 450 healthcare professionals from more than 85 countries have received training in the diagnosis and management of hemophilia and other inherited bleeding disorders.

Improving Safety and Supply

Find out what is being done to promote treatment safety and supply for all those that live with hemophilia and other inherited bleeding disorders.

A Defining Decade

Former WFH president Brian O'Mahony recounts how the WFH expanded its mandate to develop programs, with a global reach, that look years into the future.

Achieving Treatment for All

In this final video in the 50th anniversary series, former WFH president Mark Skinner explains the WFH vision to achieve Treatment for All.

For information on ordering the full series please contact wfh@wfh.org.

Sign up or renew your WFH membership as a sustaining member and help us close the gap in care.



www.wfh.org/membership

Contributions to the campaign can be made:

Online at www.wfh.org/closethegap

By mail World Federation of Hemophilia
1425, boul. René-Lévesque Ouest
Suite 1010, Montréal, Québec
H3G 1T7, Canada

By fax +1 (514) 875-8916

By phone +1 (514) 875-7944

Close the Gap campaign 2012-2014

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Jan Willem André de la Porte, WFH patron
Alain Weill, WFH president

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Frank Schnabel, III
Gina Schnabel
Marie-France VanDamme

Charles Carman, WFH president, 1988-1993
Patsy Carman

Brian O'Mahony, WFH president, 1994-2004
Mark W. Skinner, WFH president, 2004-2012

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Deon York

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The WFH is grateful to our corporate partners for their support of the WFH 50th anniversary.