

Be part of the vision.



CAMPAIGN BULLETIN

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Megan Adediran, founder and president of the HFN and WFH Close the Gap Campaign regional co-chair, addresses the local media on World Hemophilia Day.

NIGERIA: BUILDING THE FOUNDATION FOR CARE

At this point in time, less than two per cent of the estimated 16,000 people with hemophilia in Nigeria have been identified. The vast majority that have been diagnosed were identified as a result of the hard work and determination of the Haemophilia Foundation of Nigeria (HFN). The HFN was founded in 2005 by Megan Adediran, a mother of two boys with hemophilia, Isaac and Timothy.

Nigeria is the first country selected to be part of the new World Federation of Hemophilia (WFH) Cornerstone Initiative (read more on page seven of *Hemophilia World*). During the next three to four years, the Nigerian bleeding disorders community will benefit from WFH expertise in three areas:

- DEVELOPING AND IMPROVING DIAGNOSIS CAPACITY;
- PROVIDING BASIC TRAINING TO HEALTHCARE PROFESSIONALS ON THE MANAGEMENT OF BLEEDING DISORDERS; AND
- STRENGTHENING THE NATIONAL PATIENT ORGANIZATION.

Cornerstone Initiative activities started in Nigeria, in February of this year, with an educational symposium on hemophilia for healthcare professionals. A three-day training session on laboratory diagnosis occurred at the end of July. Following this, a skills-training session on advocacy, fundraising, and good governance was held for HFN board members.

Nigerians with a bleeding disorder have almost no access to treatment products and still face stigma in their local communities. Megan and the HFN are working hard to break the stigmas currently associated with bleeding disorders by encouraging patients and their families to tell their stories and letting them know that they are not alone. Nigerians now have a source of information, support, and hope. Vast needs remain, however, and the partnership between the WFH and the HFN continues.

This is the first step for Nigeria, going from no care at all, to the creation of basic care. As both the HFN and the level of care are strengthened, Nigeria will continue to move along the WFH's Continuum of Development (see diagram on page two) to a truly sustainable nation care program. With this, the WFH will be one step closer to its vision of Treatment for All.

The work to identify the remaining 98 per cent of hemophilia patients in Nigeria continues. You can help Megan and the HFN close the gap in care.

Please visit www.wfh.org/closethegap to learn more.

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

STRENGTH IN NUMBERS: THE FOUNDING OF THE HAEMOPHILIA FOUNDATION OF NIGERIA

Megan Adediran was motivated to start a hemophilia patient organization following her experiences with her older son Timothy. Very little was known about hemophilia in Nigeria when Timothy was born, even doctors did not have any answers for Megan's questions. He was not properly diagnosed with severe hemophilia A until he was seven years old and therefore suffered needlessly. Her family lost 13 boys over two generations due to undiagnosed hemophilia.

Desperate for help and answers, Megan reached out to the global bleeding disorders community for support. Through this international network, which included the WFH, Megan learned about hemophilia and different treatment options. She was then able to better advocate for the level of treatment that Timothy required.

Assad Haffar, WFH deputy programs director and regional program manager, Middle East and Africa, encouraged Megan to seek out and join together with other families to form a national patient group.

PATIENT ORGANIZATION
IS A CRUCIAL ELEMENT
IN BREAKING THE BARRIER
OF ISOLATION THAT SO
OFTEN IS A CHALLENGE
TO ACCESSING CARE.

THE WFH CONTINUUM OF DEVELOPMENT

LIMITED OR NO CARE

CORNERSTONE
INITIATIVE

COUNTRY PROGRAMS

GLOBAL ALLIANCE
FOR PROGRESS

SUSTAINABLE NATIONAL
CARE PROGRAMS

HELPING THE WFH CLOSE THE GAP IN CARE AROUND THE WORLD

In January, the WFH proudly introduced our Close the Gap Campaign regional co-chairs. Having already made remarkable contributions to improving care for people with bleeding disorders in their local, national, and regional communities, the Campaign regional co-chairs were the ideal choice to become Campaign ambassadors. The WFH is a truly global family and the Campaign regional co-chairs are dedicated to bringing this message of solidarity across all borders.

For the past several months, our Campaign regional chairs have been reaching out to local national member organizations (NMOs), patient groups, foundations, as well as friends and families, to ensure the entire global bleeding disorders community is aware of how they can participate in the Close the Gap Campaign and help advance our common cause of Treatment for All.

Visit www.wfh.org/closethegap to find out who the Campaign regional chairs are in your area.



1. A SAHF member shows his support during the 2013 Argus Bicycle Race.
2. Yan de Maroussem and Dean Rosalie on their trek.
3. Asraf Caunhye, HAM president, and Bradley Rayner, SAHF national chairman and WFH Close the Gap Campaign regional co-chair.
4. Asraf, Yan and Bradley at the finish line of Yan's Tour de l'Île.

WFH TWINS HELP TO CLOSE THE GAP IN SOUTH AFRICA AND MAURITIUS

This year, the Haemophilia Association of Mauritius (HAM) began its WFH twinning partnership with the South African Hemophilia Foundation (SAHF). During a recent workshop on strategic planning, Asraf Caunhye, HAM president, proudly presented Bradley Rayner, SAHF national chairman and WFH Close the Gap Campaign regional co-chair, with a cheque of US\$2,000 for the WFH Close the Gap Campaign. The Mauritian Minister of Health and Quality of Life was also on hand

for the official presentation of the hemophilia treatment protocol which will ensure priority treatment during a bleed.

Accredited as a NMO in 2012, HAM is one of the newest members of the WFH. Their enthusiasm and dedication to raising awareness and improving care for Mauritians with a bleeding disorder has been remarkable. They have initiated a number of events focused on sporting activities, which have proved to

be very successful in engaging all Mauritians. In 2012, Yan de Maroussem ran the perimeter of the entire island of Mauritius non-stop to raise awareness and funds for Mauritian hemophilia community. Yan was in good company during his Tour de l'Île as he was joined by supporters at various points in his journey, including Dean Rosalie. Dean, a young severe hemophilia A patient, proudly ran alongside Yan for two kilometers.

RAISING AWARENESS ON WORLD HEMOPHILIA DAY IN MEXICO

On World Hemophilia Day, April 17, the Mexican Federation of Hemophilia (*Federación de Hemofilia de la República Mexicana*) reached beyond its own community to raise awareness about bleeding disorders. Martha Patricia Monteros Rincón, secretary of the Mexican Federation and Close the Gap Campaign regional co-chair for the Americas, appeared on CNN en español, a Spanish-language news channel with an audience of 40 million viewers.

Martha used this exciting opportunity to raise awareness about bleeding disorders and the importance of supporting WFH programming. "We need to raise global awareness about the importance of supporting the Close the Gap campaign so we can help more patients in countries without adequate care," said Martha. "With the help of our friends and family we can save many lives."

Over the last two decades, Martha has helped improve access to care and treatment for the bleeding disorders community in Mexico. She has advocated for and achieved insured care for children with bleeding disorders in her country, and has promoted care and treatment for all patients in Mexico.

IN 2012, MARTHA WAS THE WINNER OF THE WFH INTERNATIONAL FRANK SCHNABEL VOLUNTEER AWARD. IT IS GIVEN TO AN INDIVIDUAL WITH A BLEEDING DISORDER, OR TO A FAMILY MEMBER, WHO HAS BEEN INVOLVED IN THE WORK OF THE WFH FOR A NUMBER OF YEARS, AND HAS CONTRIBUTED SIGNIFICANTLY IN FURTHERING THE MISSION AND GOALS OF THE WFH.



Martha Patricia Monteros Rincón, secretary of the Mexican Federation of Hemophilia and Close the Gap Campaign regional co-chair for the Americas.



President Malou Formalejo addresses the audience during the HAPLOS general assembly.



A HAPLOS volunteer during the Yakult Marathon, raising awareness about bleeding disorders, HAPLOS, and closing the gap in care.

CLOSING THE GAP THE HAPLOS WAY IN THE PHILIPPINES

Under the leadership of campaign regional co-chair Rey Sarmenta, the Hemophilia Association of the Philippines for Love and Service (HAPLOS) has become a valued supporter and partner of the WFH Close the Gap Campaign. HAPLOS President Malou Formalejo spoke about the campaign during the 2013 HAPLOS General Assembly. In solidarity with the global bleeding disorders community, she “passed the hat” to all in attendance. HAPLOS members gave what they could, with open hearts. All contributions will be given to WFH Close the Gap Campaign.

The Philippines was one of the very first countries to participate in the WFH Global Alliance for Progress (GAP) Program and has greatly benefited from other WFH programs. The Filipino bleeding disorders community is participating in the Campaign as a way to give forward to others who are living with a gap in care. They want to help ensure other WFH NMOs and members of the bleeding disorders community will be able to benefit from WFH programming.

“My personal understanding of what closing the gap means is simply shortening the journey from ‘having disability’ to ‘developing ability’ and eventually to ‘sharing ability’. I take this WFH initiative therefore as a campaign to broaden our reach of closing the gap not only beyond ones borders or boundaries but beyond ones limitations,” said Rey. “In HAPLOS we call it ‘living beyond limits’, meaning to live a life of overcoming our difficulties, going beyond ourselves and reaching out to others.”

“CLOSING THE GAP TO ME THEREFORE IS FIRST, TAKING CARE OF OURSELVES AS NMOs AND SECOND, JOINING THE GLOBAL CAMPAIGN THAT WILL REACH OUT TO THE REGIONS WHO NEED MOST IN CARE FOR BLEEDING DISORDERS.”

50 YEARS OF ADVANCING TREATMENT FOR ALL: WFH’S 50TH ANNIVERSARY WEBCAST



Past WFH presidents Brian O'Mahony (left) and Mark W. Skinner (right), along with Alain Weill (centre), current WFH president.

To commemorate its anniversary, the WFH launched a webcast on June 25, the day the WFH was founded. This webcast features presentations given by past WFH presidents Brian O'Mahony and Mark W. Skinner, along with Alain Weill, current WFH president.

Visit www.wfh.org/50 to see these past and present WFH presidents talk about their personal experiences, highlight important WFH events from the past 50 years, and explore the future vision for our community.

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

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