

CLOSE THE GAP

Campaign 2012-2014

Be part of the vision.



CAMPAIGN BULLETIN

October 2014 / No. 6



Frank Schnabel IV, grandson of WFH founder Frank Schnabel, selects our grand prize winner during the WFH 2014 World Congress.

50,000 THANK YOUS: DELEGATES MAKE THEIR MARK TO HELP CLOSE THE GAP

We would like to give a tremendous thank you to all the delegates who made their mark at the WFH 2014 World Congress. More than 250 participants showed their support for the WFH mission by making a donation to our Close the Gap Campaign in Melbourne. Participants once again had the opportunity to mark their country of origin on the grand WFH world map and enter their names in a draw for a free trip and registration for the WFH 2016 World Congress in Orlando, USA. This congress's version of the popular world map featured the state of diagnosis in a sampling of WFH member countries from around the world. **See more on page 3.**

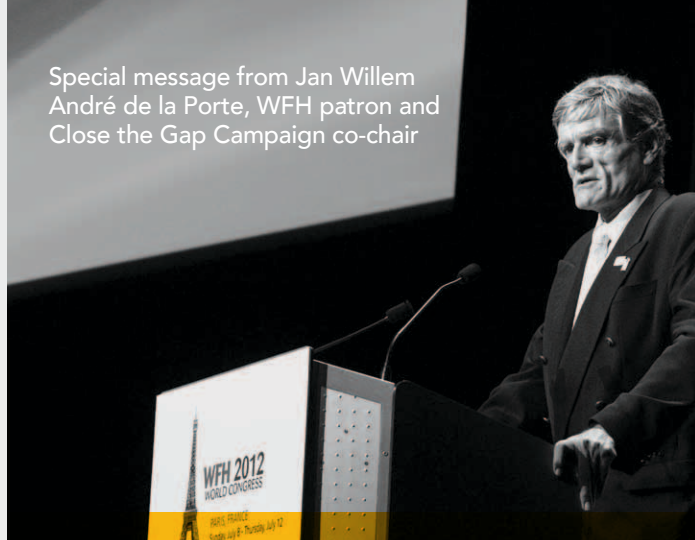
The WFH launched the Close the Gap Campaign in 2012 to raise funds for our next decade of development programs. The campaign has a three-year goal to raise \$5 million—\$1.5 of which is expected to come from a special community campaign dedicated to gathering supporting directly from the global bleeding disorders community. Since the campaign's launch in 2012, it has raised over US\$1.2 million, leaving \$250,000 left to raise by the end of December to reach our campaign goal. During the 2014 congress, delegates donated close to US\$17,000 to help Close the Gap in care worldwide. Gifts ranging from 25 cents to US\$5,000 were received from donors from 67 different countries.

JOIN US ON FACEBOOK TO SEE PHOTOS OF CONGRESS DELEGATES MAKING THEIR MARK ON THE WFH WORLD MAP. BE SURE TO TAG YOURSELF AND LET EVERYONE KNOW HOW YOU MADE A DIFFERENCE!

Many in attendance were inspired by the remarkable generosity of WFH patron and campaign co-chair Jan Willem André de la Porte and his "Patron's Challenge". Every contribution has been tripled and the total raised for Congress 2014 is an outstanding \$51,000! Jan Willem's challenge continues until the end of 2014.

YOU CAN SHOW YOUR SUPPORT AND MAKE YOUR DONATIONS AT ANY TIME ON LINE AT WWW.WFH.ORG. YOUR GIFT IS STILL ELIGIBLE TO BE MATCHED BY OUR PATRON AND WILL BE TRIPLED BY THIS REMARKABLE AND INSPIRING LEADER! SEE MORE ON PAGE 2. WILL YOU RISE TO THE CHALLENGE?

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



WILL YOU RISE TO THE CHALLENGE?

WFH patron and campaign co-chair Jan Willem André de la Porte launched the Close the Gap Campaign with a remarkable challenge to the entire bleeding disorders community. To help the WFH reach those who live in regions where the gap in care is greatest, he challenged WFH friends and supporters to make a donation to the Close the Gap Campaign.

Jan Willem has first-hand knowledge of the importance of diagnosis and access to care. His home country of South Africa is a region where nearly 40% of people with a bleeding disorder remain undiagnosed.

HOW IT WORKS

\$ + \$\$ = \$\$\$

Make your gift to the Close the Gap campaign before December 31, 2014 and Jan Willem will triple it! This means:

Your gift of \$50 = \$150 = more training

**Your monthly gift of \$35 (\$420/year)
= \$1,260 = more patients diagnosed
every year**

**Your gift of \$500 = \$1,500 = more
Humanitarian Aid reaches those who
need it most**

To send your donation use the envelope in this issue of *Hemophilia World* or make a secure donation online at www.wfh.org/donate

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

GIVE TO CLOSE THE GAP IN CARE



**Give \$125 to provide 2 days of
training for a medical team**

Please read about the IHTC Program on page 22 of *Hemophilia World* to learn more about how training local medical teams leads to improved care.



**Give \$35 per month to help diagnose
10 people with a bleeding disorder**



**Give \$500 to help ship 30,000 IUs of
Humanitarian Aid to West Africa**

Please read more about the Humanitarian Aid Program on page 6 of *Hemophilia World*.

THE SCHNABEL FAMILY REAFFIRMS ITS COMMITMENT TO CAMPAIGN SUCCESS

The success of fundraising at the WFH 2014 World Congress was especially meaningful as the final contribution of the congress was made by Frank Schnabel III, on behalf of the entire Schnabel family. He expressed his family's commitment to the campaign during the opening ceremony where he said:

"At the 2012 World Congress, my sister Gina was present and she announced that our family had made a personal pledge to the Close the Gap Campaign and the Cornerstone Initiative. I would urge you all to do the same as the campaign is in its final year and the three-year goal of \$5 million is within reach.

**MY FATHER ONCE SAID, 'TOGETHER WE WILL EMERGE
VICTORIOUS'. AND WHILE VICTORY IS MORE THAN AN
ARM'S LENGTH AWAY, IT IS CLOSER THAN IT HAS EVER
BEEN BECAUSE OF THE WORK OF THIS COMMUNITY.'**



Frank IV (front left) and Frank III (second left) with members of the WFH Board.

Attending the congress with his son, Frank IV, both participated at various sessions and events throughout the Congress, including the opening ceremony, WFH Volunteer Awards ceremony, a pre-Congress bakeoff organized by the Australian Youth committee, as well as meeting with WFH national member organization leaders from South America.

MAPPING THE GAP IN DIAGNOSIS

Great strides have been made in the treatment and diagnosis of bleeding disorders around the world, yet there still exist vast gaps in care from one country to another. For the 2014 World Congress, we unveiled a new look for our interactive world map to visually show congress participants the state of diagnosis in different areas across the globe.

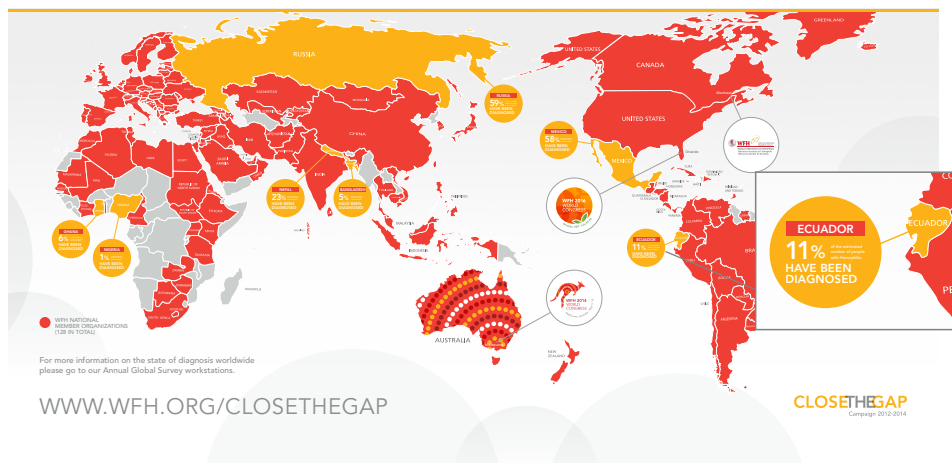
Currently, in most developed countries, patients can expect to receive a prompt proper diagnosis and treatment. **But for people in developing countries simply finding out they have a bleeding disorder is difficult.** Some countries lack the necessary medical knowledge, infrastructure and resources to make a proper diagnosis even possible.

From 1 per cent of estimated patients diagnosed in Nigeria to 59 per cent in Russia, the world map reminded all participants why their contributions are so important. Participants from around the world who made a campaign donation

MAKE YOUR MARK
ON THE WFH WORLD MAP

HELP US
RAISE
\$500,000
IN 2014

HELP TO
DIAGNOSE
50,000 PEOPLE
BY 2023



THE WFH HAS SET A TARGET TO DIAGNOSE 50,000 NEW PATIENTS BY 2023 AND TO ENSURE THAT 50 PER CENT OF THOSE NEWLY DIAGNOSED ARE FROM THE WORLD'S MOST IMPOVERISHED COUNTRIES.

at the WFH Resource Centre then proudly marked their home country on the map—a powerful symbol of global solidarity.

For more information on the state of diagnosis worldwide, please see our new interactive world map at www.wfh.org

TRIP OF A LIFETIME

Last year, Ernestine Fuller attended the National Hemophilia Foundation's annual meeting where she entered and won a draw for a free trip and registration to the Melbourne congress. She was thrilled—travelling to Australia has been a lifelong dream. Ernestine had hip-replacement early this year and was on crutches when she learned about her win, but she was determined to make the trip. “My orthopedic surgeon thought I was crazy when I told him I had to be off my crutches by WHF Congress 2014 event in Australia. He said he had never seen so much determination to make a full recovery. I told him an opportunity like this only comes around once in a lifetime. I explained to him that living with a bleeding disorder can be challenging at times, especially now that I have joint bleeds, but I refuse to let it deter me from learning and advocating where necessary.”

Ernestine is a member of the Maryland and Washington D.C. chapters of the National Hemophilia Foundation and was elected to the Board of Directors for the Hemophilia Association of the Capital Area in 2013.

Our Congress winners

This Congress New Zealand was deemed to be the country with the most generous heart. The New Zealand delegates were awarded the WFH International Donation World Cup for the most donors at Congress, relative to population size. Second place was Trinidad and Tobago while Sweden was third.

Special activities featured at the WFH Resource Centre included daily draw prizes and a grand prize. Our winners:

- Daily draw prizes were won by Abdulaziz Sherif (Ethiopia), Theresa Stevens (New Zealand) and Dawn Thorp (Australia)
- The Grand Prize—a trip to the WFH 2016 World Congress in Orlando, USA) was won by Peter Pustoslemsek of Germany. Peter demonstrated exceptional generosity during the congress. He was the very first to make a campaign contribution during the event and then gave away his grand prize to another congress delegate. Read his story on page 30 of *Hemophilia World*.



Left: Ernestine Fuller of Washington D.C., USA picks the Day 1 draw winner.

Right: New Zealand delegates celebrate their WFH World Cup win during the Congress Farwell dinner with a stirring performance of the haka, the traditional war dance from Maori people of New Zealand.

CLOSE THE GAP: CORPORATE CAMPAIGN WELCOMES NEW PARTNERS TO THE GLOBAL ALLIANCE FOR PROGRESS

The Close the Gap Campaign which runs from 2012 to 2014 has an overall goal of \$5 million.

Of this, \$3.5 million is the goal for the corporate campaign appeals to support the launch of the second decade of GAP, the WFH Research Program and initiatives related to the WFH's 50th anniversary, such as the 50th anniversary video series.

As of June 30, 2014 \$US3.290 million has been pledged or given in support of these three areas, reflecting 93% of the Corporate Campaign goal.

Three corporate partners joined a core group of seven that have renewed their support for the second decade of the flagship WFH program. The three new partners, Kedrion, SOBI and Novo Nordisk were welcomed into the GAP program at the May 15 GAP President's Strategic Council (PSC) meeting held in Melbourne at the WFH 2014 World Congress.

In the second decade of the GAP Program the focus is on improving diagnosis for all bleeding disorders, improving treatment in the world's poorest regions, as well as building on the achievements to date. The

overarching goals for the second decade (2013-2022) of GAP are to:

- Increase by 50,000 the worldwide number of people identified/diagnosed with a bleeding disorders;
- Ensure that 50 per cent of those newly diagnosed are from the world's most impoverished countries.

The WFH Research Program welcomed a new sponsor this year, Grifols, which joined Bayer, Baxter, Biogen Idec Hemophilia and the Hemophilia Center of Western Pennsylvania. Thanks to these supporters, the WFH Research Program is encouraging and supporting clinical research that will build the knowledge base for the optimal management of inherited bleeding disorders through two components: Epidemiological research and a clinical research grant competition.

Thank you to all our partners for supporting the WFH mission and vision.

To support the Close the Gap Corporate Campaign, become a partner in the second decade of GAP, or to support the WFH Research Program please contact Dolly Shinhat-Ross at dshinhat@wfh.org



In anticipation of the next World Congress in Orlando, U.S.A. in 2016, over 100 congress attendees from the U.S. gathered together in Congress Exhibit Hall for a special group photo. Hosted by the National Hemophilia Foundation, the WFH's national member organization in the U.S., the WFH 2016 World Congress is being held in the United States for the first time in 20 years.

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

CO-CHAIRS

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

HONORARY CAMPAIGN COMMITTEE MEMBERS REPRESENTING WFH PAST PRESIDENTS

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