



WFHUSA

WORLD FEDERATION OF HEMOPHILIA USA



YEAR-END REPORT 2020

wfhusa.org

THE ACADEMY OF
21ST CENTURY
LEARNING

SENSOR MICROWAVE & PRESETS

Sensor Reheat | Frozen Pizza | Frozen Entrée

Potato | Rice | Veggie

OUR MISSION

WFH USA advances the global mission of the World Federation of Hemophilia (WFH) in the United States

The two organizations collaborate to support a number of activities that are central to their shared vision of Treatment for All: that one day, all people with bleeding disorders will have access to care, no matter where they live. These activities include the WFH Humanitarian Aid Program, the WFH Research Program, and WFH Training and Education Program.

WFH USA also offers a scholarship program to empower young women who have the potential to become future leaders of our community, as well as grants for US-based multidisciplinary healthcare professionals to connect with the global community and further develop their leadership and expertise.

THANK YOU FOR HELPING US ADAPT TO A NEW REALITY

Support our work

Donate today at give.wfh.org/give-usa

Sign up to receive regular updates from the global bleeding disorders community at wfh.org/connect

Charitable solicitations for the common purpose of WFH and WFH USA within the U.S are conducted through WFH USA, a 501(c)3 affiliated entity.



PRESIDENT'S REPORT



Greetings,

The COVID-19 pandemic has had a significant impact on our community. Supply chains delivering donated factor to those in need ground to a crawl, the convention halls where we would meet to renew friendships and exchange knowledge sat dark and empty, and safety measures made traditional outreach and advocacy programs in developing countries impossible overnight. The WFH adapted to this new reality by shifting training and resources online and by collaborating closely with NMOs to provide support in the most effective ways possible.

2020 brought unforeseen challenges to those living with little or no access to care. In their time of need we turned to the US community for support and your generous response humbled and inspired all of us. You who are our Community Partners continue to provide the foundation for so many life-changing programs. Our corporate supporters continue to heed our call to provide donated product and funding that helps to ensure all patients have access to treatment regardless of where they were born. My heartfelt thanks to all the US citizens, healthcare professionals and their friends and families who made individual donations. We're grateful for all of you and the countless US volunteers who give so freely of their time and expertise

It's important to be taking steps towards incorporating a broader range of voices. Diversity initiatives will be taking center stage in our upcoming strategic planning sessions, which will help guide us in the coming years. We are looking forward to this next step and to being a stronger voice for our community members living in historically marginalized communities at home and abroad.

As always, I value your input. If you want to relate your experience to us or have a suggestion on how we can serve our community better, please reach out to me at estolte@wfh.org.

On behalf of the WFH USA Board of Directors, thank you for all that you do for our community. As you will read in the following pages your support allows us to always be there for those living with little or no access to treatment and for that we are forever grateful.

A handwritten signature in black ink that reads "Eric Stolte".

Eric Stolte
WFH USA President

Board of Directors

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Eric Stolte

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Strategic & Community Partnerships

YOU HELP US BE
THERE FOR THOSE
WHO NEED US MOST



Nairobi, Kenya

Photo taken before restrictions in place

In 2020, under challenging conditions, 146 million IUs of donated product, as well as the first vials of emicizumab, were delivered via the WFH Humanitarian Aid Program, treating 20,000+ patients

The lack of access to factor and treatment for people affected by a bleeding disorder in developing countries like Kenya is an urgent and public health challenge we seek to address everyday.

Judy Chege of Nairobi already lost one son to complications arising from his bleeding disorder, and she was determined not to lose another. Her son Steve faced an uncertain future until he was referred to Dr. Kibet Shikuku, chairman of the Kenya Hemophilia Association who, thanks to the contributions of our partners, was able to provide him with donated factor.

We are happy to report that Steve is thriving. He is sharing his personal journey as part of outreach and advocacy programs in his community and is poised to be among the country's next generation of leaders.

“*What I don't want? Don't let my son die.*”

- Judy Chege, pictured above
with her son Steve

The WFH Humanitarian Aid Program improves the lack of access to care and treatment by providing much-needed support for people with inherited bleeding disorders in developing countries. By providing patients with a more predictable and sustainable flow of humanitarian aid donations, the WFH Humanitarian Aid Program makes it possible for patients to receive consistent and reliable access to treatment and care. WFH and WFH USA collaborate to manage and control the WFH Humanitarian Aid Program.

None of this would be possible without the generous support of Sanofi Genzyme and Sobi, our Founding Visionary Contributors; Bayer, our Visionary Contributor; Grifols and Roche, our Leadership Contributors; and our Contributor, CSL Behring. To learn more about the WFH Humanitarian Aid Program, visit www.treatmentforall.org

YOU HELP US PROVIDE VITAL EDUCATION AND TRAINING

Bleeding Disorders
Organized by
Department of Hematology SGPGI
In Association with WFH
Date – 30th Jan, 2nd Feb 2020
Venue – I Block Department
of Hematology



Lucknow, India

Photo taken before restrictions were in place

Our education and training initiatives are a vital component in building capacity to provide sustainable comprehensive care and treatment for people with inherited bleeding disorders.

In 2020, the WFH pivoted quickly to offer close to 100 workshops and seminars virtually, ensuring participants could learn in a safe environment.

Pandemic restrictions meant that scheduled in-person events had to be cancelled. We were able to bring these events online with little delay—avoiding a potentially devastating gap in learning, while opening up educational opportunities to a broader global audience.

In a time of great uncertainty our COVID-19 webinars were a source of trusted information for our community. Our first webinar, focusing on immediate health and access to treatment issues, was hosted less than three weeks after the pandemic took grip and was attended by over 2,000 community members. From this successful starting point we continued offering relevant and timely sessions and online workshops for all members of our community.

A Virtual Success Story

Though we had to cancel the 2020 WFH World Congress, we turned this setback into a success! A record number of people participated in the WFH Virtual Summit. More than 8,550 participants from 160 countries took part in over 50 sessions over six days. A big thank you to all who chose to support our work by making a gift of their registration fees!



CONNECTING
THE GLOBAL
BLEEDING
DISORDERS
COMMUNITY



**YOU HELP US LAY THE
FOUNDATION FOR A
BRIGHTER FUTURE**

Dakar, Senegal

Photo taken before restrictions in place

WFH Research and Data Collection efforts seek to provide evidence to inform the clinical management of people with bleeding disorders and support advocacy efforts aimed at improving access to treatment and care.

The WFH is committed to providing evidence-based guidance to help establish and promote clinical care in HTC's around the world. In 2020, we published updated practice guidelines for both hemophilia and VWD and supported a number of HTC's in their efforts to launch or improve their clinical data collection efforts through the World Bleeding Disorders Registry (WBDR). Today, the database includes more than 8,100 people with hemophilia from 90 treatment centres in 42 countries.

In Senegal, data on bleeds and treatments was collected during treatment, but inconsistency and low volume made it hard for physicians to get a good grasp of the situation in the country's bleeding disorder community.

Thanks to funding provided by the WFH, the HTC in Dakar was able to implement the WBDR's reliable data collection system, significantly improving the accuracy and ease-of-entry of bleeding disorders data in Senegal.

Resources for All

A collaborative effort between patients and healthcare professionals, the WFH Guidelines for the Management of Hemophilia, 3rd edition, offer practical recommendations on diagnosis and care of hemophilia.

WFH Treatment
Guidelines

**HEMOPHILIA
GUIDELINES FOR ALL**



RESOURCE HUB

www.wfh.org/TGresourcehub

To learn more about the World Bleeding Disorders Registry, visit www.wfh.org/wbdr

**YOU HELP US BE
THERE TO GIVE
VOICE TO WOMEN**



The WFH is working to ensure greater inclusion for women and girls with bleeding disorders in the community. We are listening to the stories and challenges they face accessing care and treatment and bringing people together to learn, grow, and find solutions

For the last ten years, the Susan Skinner Memorial Fund has invested in our community's young women, recognizing their voice and perspective are crucial to our future growth. In late 2019, a task force was mandated to assess the program's outcomes and to seek new opportunities to cultivate leadership and promote engagement of women in the global bleeding disorders community.

Their recommendations included a pilot to broaden the age eligibility, increased efforts to promote the program both in the US and around the world, and new opportunities to engage past recipients, including a mentorship component for future scholars. The new era begins in 2021. Stay tuned!

A Place of Their Own

The WFH Global Summit on Women and Girls with Inherited Bleeding Disorders brings together women affected by bleeding disorders, patient representatives, and healthcare professionals to exchange on the realities of care and treatment around the world. Over 1,200 attendees participated in the first summit in 2020.

WFH Global Summit on

women & girls

with inherited bleeding disorders

UNITED IN SOLIDARITY: OUR COMMUNITY PARTNERS



NATIONAL HEMOPHILIA FOUNDATION

The National Hemophilia Foundation helps advance our mission on several fronts. Their deepening support is inspiring others to follow their lead in so many ways. As a founding champion of the NHF Chapter Challenge they lead the way for the US community to support our work. Their commitment to equity is demonstrated in their steadfast support of the Cornerstone Initiative, which lays the foundation for care in the world's most underserved regions, as well as programs that aim to raise awareness and improve care of women with bleeding disorders. We thank their staff and leadership for their deep and continuing engagement with our programs including the Twinning Program and the Global Summit for Women and Girls with Inherited Bleeding Disorders.



Hemophilia of Georgia's partnership with us is heading into its fourth decade. They were there in the beginning, supporting our efforts to deliver humanitarian aid donations and even giving us space in their fridge to store product. They went on to inspire the US community through becoming a founding Chapter Challenge champion in 2016 and they continue to stand at the forefront of new programs. In 2020 they funded critical psychosocial training sessions to provide mental health professionals with tools to support the community through the pandemic, as well as a series of workshops designed to help our member organizations advocate effectively in the time of Covid-19. They continue to demonstrate their commitment to our future by investing in leadership training, including an innovative video series about bleeding disorders and relationships. We thank their staff for their continued engagement as board and committee members and workshop facilitators.



The Hemophilia Alliance's deep commitment to education and training is apparent in their support of our programs. They promote knowledge exchange thorough the Travel Grant Program, which enables healthcare professionals who are not externally funded to attend WFH training events. In 2020, they helped us make our Treatment Guidelines more accessible by funding the creation of the online Resource Hub, which features interactive guidance and videos from leading global experts in hemophilia care. We want to take this chance to say thank you to Joe Pugliese for his service as a WFH USA Board Member, your dedication, humor and energy will be missed!

2020 FINANCIAL REPORT



IWFH USA 2020 FINANCIAL REPORT

In 2020, we received \$3,774,681 in contributions from dedicated donors and partners towards the joint and coordinated activities of the WFH and WFH USA (\$2,333,930 in 2019). These include the WFH Humanitarian Aid Program, the WFH Research Program and the WFH Training and Education Program. From these contributions we granted \$3,686,552 to the WFH as needed to carry out its responsibilities with respect to the joint programs (\$2,228,851 in 2019). The increase was attributable to having experienced a full year with our two new Humanitarian Aid partners: Bayer and Roche. We also had a good year for charitable donations with \$302,061, compared to \$220,417 in 2019. In 2020, we obtained a surplus of \$59,060 versus a surplus of \$10,640 in 2019. WFH USA remains in sound financial health with year-end unrestricted assets of \$311,450 (\$252,390 in 2019).

Despite the major logistical challenges created by the COVID-19 pandemic, the WFH Humanitarian Aid Program team worked tirelessly to continue delivering care to those who needed it most. In 2020, 146.5 million IUs of factor (241 million IUs in 2019) and 27 thousand vials of emicizumab were provided to patients in 69 developing countries. The majority of these donations, worth \$394,273,901, are included in the audited financial statements of WFH USA (\$437,273,143 in 2019).

The donations to the Susan Skinner Memorial Fund (SSMF) totaled \$52,766 in 2020 (\$49,724 in 2019). This brought the endowment fund balance to \$550,651 from \$497,885 at the end of 2019. We thank all those who support this important initiative. The continued growth of this fund allows us to invest in our women leaders to the benefit of our entire community. WFH USA continues to count on the generosity of those in our community who donate their time, energy, and professional expertise to our product donation program and to the WFH USA Board of Directors. The estimated monetary value of the volunteer services was at \$271,820 in 2020 (\$349,545 in 2019).

The dedication and loyalty of our American community humbles and inspires us. Without you, WFH USA could not continue advancing the global mission of the WFH to improve access to care for people with bleeding disorders around the world.

You can find our complete financial statements at www.wfhusa.org

2020 CHAPTER CHALLENGE CHAMPIONS



In 2016 we launched the NHF Chapter Challenge and over the past five years, our two Founding Champions and NHF Chapters contributed over \$735,000 in support of WFH global development programs. 2020 was a challenge, even for champions, but with allies like you, we know we are never alone.

Thank you to all the Chapters who supported us last year.
We look forward to where our partnership will take us next! Thank you!

Founding Champions

National Hemophilia Foundation
Hemophilia of Georgia

Five-time Champions

Bleeding Disorders Alliance Illinois
Hemophilia Association of the Capital Area
Hemophilia Foundation of Michigan
Hemophilia Foundation of Southern California
Hemophilia of Indiana Inc.
Hemophilia of North Carolina
Hemophilia of South Carolina
Lone Star Bleeding Disorders Foundation
Nevada Chapter of the National Hemophilia Foundation
Pacific Northwest Bleeding Disorders
Rocky Mountain Hemophilia & Bleeding Disorders Association
Virginia Hemophilia Foundation

Four-time Champions

Alaska Hemophilia Association
Colorado Chapter of the National Hemophilia Foundation
Florida Hemophilia Association
Gateway Hemophilia Association
Hemophilia Alliance of Maine, Inc.
Hemophilia Foundation of Greater Florida, Inc.
New England Hemophilia Association

Three-time Champions

Great Lakes Hemophilia Foundation
Kentucky Hemophilia Foundation, Inc.
Mary M. Gooley Hemophilia Center

Two-time Champions

Connecticut Hemophilia Society
Hawaii Chapter of the National Hemophilia Foundation
Sangre de Oro, Inc. Hemophilia Foundation of New Mexico
Southwestern Ohio Hemophilia Foundation

2020 First-Time Champions (Welcome!)

Hemophilia Foundation of Idaho
Nebraska Chapter of the National Hemophilia Foundation
Texas Central Hemophilia Association
Tri-State Bleeding Disorder Foundation
West Virginia Chapter of the NHF
Western Pennsylvania Chapter, NHF

THANK YOU TO OUR DONORS

The support we receive from across the US allows us to ensure every child with a bleeding disorder receives the care they need, regardless of where they live.
Your support signals to the world that we are united in our commitment to Treatment for All.

\$250,000.00 +

Hemophilia of Georgia

\$100,000.00 +

The Hemophilia Alliance

\$75,000.00 +

National Hemophilia Foundation

\$50,000.00 +

Glenn and Beatrice Pierce

The Marketing Research Bureau

\$10,000.00 +

Anonymous

Mark Skinner and James Matheson

\$7,500.00 +

The Blackburn Giving Fund

Phillips 66

\$5,000.00 +

Donald and Barbara Goldman

New England Hemophilia Association

\$2,500.00 +

Lone Star Bleeding Disorders Foundation

Frank Schnabel IV and Lillian Schnabel

\$1,000.00 +

Paula Bell and Rob Christie

Seng H. Cheng

Colorado Chapter of the National Hemophilia Foundation

Florida Hemophilia Association

Gateway Hemophilia Association

Great Lakes Hemophilia Foundation

Hemophilia Association of the Capital Area

Hemophilia Foundation of Idaho

Hemophilia Foundation of Michigan

Hemophilia Foundation of Southern California

Hemophilia of Indiana Inc.

Edward Johnston

Craig Kessler

Barbara Konkle and Peter Kollros

Mary M. Gooley Hemophilia Center

John Murphy

Nevada Chapter of the National Hemophilia Foundation

Pacific Northwest Bleeding Disorders

Joseph Pugliese

Rocky Mountain Hemophilia & Bleeding Disorders Association

Edith A. Rosato

Dawn S. Rotellini

Kenneth Trader

Tri-State Bleeding Disorder Foundation

\$750.00 +

Phillip Kucab

Sundar Rajan Selvaraj

\$500.00 +

Alain Baumann

Bleeding Disorders Alliance Illinois

Amy Dunn

Hemophilia of North Carolina

Hemophilia of South Carolina

Elaina Jurecki

Kentucky Hemophilia Foundation, Inc.

Debra Margolin

Prasad Mathew

Mary Ann McCullough

Andy Mulvey

Nebraska Chapter of the National Hemophilia Foundation

Eric and Marion Stolte

Texas Central Hemophilia Association

Sandra Valdovinos-Heredia

Virginia Hemophilia Foundation

West Virginia Chapter of the NHF

\$250.00 +

Alaska Hemophilia Association

BioMarin Pharmaceutical Inc.

Connecticut Hemophilia Society

Jacqueline Curtis

Matt Gross

Hawaii Chapter of the National Hemophilia Foundation

Hemophilia Alliance of Maine

Jennifer Laliberté

Mary Lesh

Amy and Allen Renz

Sangre de Oro, Inc. Hemophilia Foundation of New Mexico

Southwestern Ohio Hemophilia Foundation

Western Pennsylvania Chapter, NHF

\$100.00 +

Broth

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Karen Geney

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Kathleen Gerus

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Chip Hearn

Steve and Linda Hughes

Carol K. Kasper

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Remember Steve? This is him today.

You met him on page 4, but to be honest a few lines are not enough to tell anyone's story - let alone this young man's. He has lived with uncertainty and pain for much of his life and knows the deep heartbreak of losing a brother to the complications of his bleeding disorder.

In the photo above, he is advocating for better care. He is able to do so because he is living proof of the impact that trained healthcare professionals, accurate and timely diagnosis and access to medication can have. If he was born some years earlier, before WFH training and education programs arrived and the first pallet of donated factor made its way to Kenya, his story would be much different.

WFH USA supporters helped us be there for Steve, and we continue to work for the thousands like him around the world. Thank you.

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