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Patient registries make it possible to collect longitudinal, real world data on large cohorts of patients, allowing researchers to address important research questions. Real world data—or data collected on patients outside of the traditional clinical trial—offer the benefit of providing a picture of the patient experience under routine clinical practice. In some countries, real world data are the only data possible to obtain. In other countries, real world data can be used to supplement clinical trial data. These data are a valuable addition to the arsenal of strategies we need to advance the quality of clinical care and advocacy measures for patients with bleeding disorders.

Currently, the WFH collects aggregate data provided by our national member organizations (NMO) which is published annually in the WFH Annual Global Survey. These data give a global overview of the number of patients with bleeding disorders identified and a snapshot of the level of access to care around the world.

To meet the challenge of increasing the amount and type of data available on patients with bleeding disorders, the WFH is developing the World Bleeding Disorders Registry (WBDR). The WBDR will collect individual patient level data through Hemophilia Treatment Centers (HTC). Uniform data on demographics, diagnosis, clinical, and treatment outcomes on patients will be collected. This registry is intended to collect real world data on the patient clinical experience around the globe. It will provide researchers with the capacity to compare the patient experience from country to country and within countries.

With reach to a network of over 1,000 HTCs and 134 WFH NMOs, and with access to
patients in countries with varying levels of care and access to care, the WFH is uniquely positioned to effectively conduct a global registry. Currently a pilot project, the full WBDR is expected to launch in 2017. The aim of the pilot project is to assess the feasibility of conducting a patient registry around the globe. It will assess the interest of HTCs and patients in participating, the ability of HTCs to obtain regulatory approval, and the ability to successfully add their data to a web-based data system. Forty HTCs were invited to participate in the pilot project and 31 have agreed to do so—a response rate of 78%. The countries involved in the pilot project are scattered around the globe, and include: Algeria, Argentina, Australia, Belgium, Brazil, Cameroon, Canada, Egypt, Estonia, Ethiopia, India, Indonesia, Jamaica, Kenya, Kyrgyzstan, Mali, Morocco, Philippines, Senegal, Slovenia, Sri Lanka, Switzerland, Thailand, Uganda, the U.K., U.S.A., Uzbekistan, Venezuela, Vietnam, and Zimbabwe. The pilot project is expected to be completed by the end of 2016.

“The patient registry is about bringing patients together from around the world in a cooperative fashion. It’s about all of us working as a team to further knowledge in the bleeding disorders community.”

If the pilot is successful, HTCs from all levels of economic development will be invited to join the WBDR starting in mid-2017, and patient recruitment will begin at HTCs upon ethics approval. Over the first 5-year period, from 2017 to 2022, the WBDR seeks to include HTCs from more than 50 countries, representing over 20% of all HTCs worldwide, and over 15,000 individuals with bleeding disorders.

The value of a large patient registry, such as the WBDR, lies in the utilization of the data collected. Patients who participate in the WBDR will have the opportunity to contribute to the shaping of care around the world. As the data accumulates, it will increasingly reflect the patient experience and the state of care of bleeding disorders around the world. This will be an invaluable resource for research and advocacy purposes. Anonymized data will be available to participating researchers with secure data protection to permit researchers to carry out studies on a larger number of patients than they would have access to outside the model of patient registry. Individual countries will be able to use country-specific data and country-comparative data to advocate for better care.

In the current landscape of many regional, national, and international patient registries, the harmonization of datasets is essential to compare, combine, and make the best use of our data. Despite varying objectives, many of the ongoing patient registries have common core data elements. The task of harmonizing core data elements and linking databases will require collaborative initiatives between governing bodies of existing patient registries. It will require forward thinking on how to best align data collection efforts with existing patient registries. The WFH is taking advantage of the current development period of the WBDR to align our core data set with the larger, existing patient registries around the globe in order to make future linkage easier to implement.

Combining data from the smaller and less developed countries with those of larger and more developed countries will help complete the global picture of people with bleeding disorders. Joined together, data from around the world will provide an unprecedented amount of real world data and a strong and robust platform upon which to advance patient care around the globe. Ultimately, researchers, clinicians—and most of all, patients—will benefit from the World Bleeding Disorders Registry.
Gaining further insight into the world of rare diseases

This year, the World Federation of Hemophilia (WFH) became a member of Rare Diseases International (RDI), an organization with a mission to be a strong common voice on behalf of people living with a rare disease around the world. By joining RDI, the WFH will now be part of a global alliance that lobbies and advocates for patients and the families of patients with a rare disease.

/Alain Weill, PRESIDENT

RDI is part of the United Nations (UN) NGO Committee for Rare Diseases, a body dedicated to bringing together the international NGO community, major UN agencies, national governments, academic and scientific participants, and private sector groups.

In November, I had the honour to represent the WFH at the UN, speaking at the inauguration of the NGO Committee for Rare Diseases. During this gathering, I shared with other NGOs how the WFH works with our national member organizations (NMOs) to address the challenges facing our community.

As a member of RDI, the WFH will now be part of a larger international agenda, giving voice to our 134 NMOs on the global stage. This increased access to international entities such as the UN can only further benefit WFH advocacy initiatives.

Earlier this year, I spoke at the Rare Diseases Conference 2016 in Cape Town, South Africa. It was my privilege to share the many successes and achievements that the WFH has accomplished with that community. Our NMOs are coming up with innovative initiatives to address the challenges of raising awareness about bleeding disorders. The WFH provides the link between all our NMOs to exchange best practice solutions through trainings, meetings, the Global NMO Training, and the WFH World Congress.

However, there are many rare disorders within our community that need further support. There are small patient populations with platelet disorders and factor deficiencies that are considered extremely rare. Through exchanges and experience-sharing with RDI, the WFH will be able to gain further insight into how to best support these groups.

The WFH will be able to learn from other RDI members’ experiences, and we will also share our own expertise and learnings with them. Ultimately, the goal is for us to work together as a team, and for the WHF to continue to advance our vision of Treatment for All.

A NEW ERA FOR HEMOPHILIA WORLD READERS IN 2017

The WFH is happy to announce that more Hemophilia World content will be available online for readers beginning in January 2017. Currently, Hemophilia World is published three times a year in print and online at www.hemophiliaworld.org. The new format that we are launching will feature articles and information released online weekly and monthly—as news happens. Then every September, we’ll be publishing a rich collection of the year’s most important content in a magazine called Hemophilia World Review. This new issue will replace the three issues that are currently produced.

We hope you’ll visit www.hemophiliaworld.org often in 2017 to keep in touch with what’s happening in our community. And look in your mailbox in September for Hemophilia World Review!
The World Bleeding Disorders Registry – final stages of the pilot program

In my VP Medical Column in the April 2016 issue of Hemophilia World, I announced that the World Federation of Hemophilia (WFH) would launch a World Bleeding Disorders Registry (WBRD) pilot program.

/Marijke van den Berg, MD, VICE-PRESIDENT, MEDICAL

This program has now begun and the WBDR is currently being piloted in 31 countries around the world to assess the feasibility of data collection in centres at all levels of development. With patient enrolment almost complete, the pilot project will finish by the end of 2016. The results of the pilot project to date are very promising and will be presented in poster format at the European Association for Haemophilia and Allied Disorders (EAHAD) Congress in February 2017. If the pilot is successful, the full scale WBDR—to be conducted in more than 50 countries—will be implemented in 2017.

The WBDR will generate real world data on more than 15,000 patients, from regions around the world, in the context of routine clinical care. It will be an invaluable resource for researchers to use, for both clinical research and advocacy purposes.

The WBDR is an important endeavour because despite great advances made in hemophilia care in the past 50 years, care is still sub-optimal in many instances. Patients around the world continue to suffer from increased morbidity and mortality due to bleeding into joints, muscles, the brain and other sites.

The advancement of evidence-based care of hemophilia and other rare bleeding disorders is limited by factors inherent to research in rare diseases: small samples sizes, geographical dispersion of patients and heterogeneity in the clinical course observed in patients. Combined, these factors diminish a study’s statistical power, making the generation of high quality evidence in clinical and treatment outcomes in rare diseases challenging. This has given rise to a call for global rare-disease registries.

Registries—with international collaboration between centres and countries—are an effective way to pool enough data in order to achieve a sufficient sample size to enable epidemiological and clinical research for rare disorders. The data generated from registries allows for the analysis of patient outcomes in the context of routine clinical care and real world setting. These data have the potential to improve our current quality of care, examine the patient experience longitudinally, assess the effectiveness of medical treatments and identify significant unmet needs. Increasingly, regulatory bodies around the globe are relying on real world data, including patient registry data, to inform their regulatory and reimbursement decisions, health technology assessments, and treatment guidelines.

The WBDR is the vehicle the WFH is using to respond to a call for a global patient registry to enhance data and strengthen evidence in bleeding disorders. It is intended to fill the gap in evidence by collecting an unprecedented amount of real world data, and it will be tremendously useful for generating evidence to improve the quality of care for patients with bleeding disorders worldwide.

To find out more about the WBDR, please visit www.bleedingdisordersregistry.org.

WFH CLINICAL RESEARCH GRANT PROGRAM UPDATED FOR 2017

The WFH Clinical Research Grant Program (CRGP) provides support for international clinical investigations related to inherited bleeding disorders. Since the grant program was launched in April 2013, over $430,000 has been disbursed to 10 grant recipients.

The CRGP is now in its fourth cycle of grant competition and the process has been updated in several ways for the 2017 submission year.

**RESEARCH PRIORITIES**

The WFH Medical Advisory Board and the WFH Research Committee have identified research priorities for grant applications. Submissions do not need to be limited to this list, however, research proposals that fall within these priorities are strongly encouraged.

1. Prophylaxis schedules
2. Inhibitor diagnosis and management
3. Optimal use of adjunctive therapies
4. Care of the neonate with hemophilia
5. Management of chronic hemophilic arthropathy
6. Care of hemophilia carriers
7. Pain management
8. Role of physical activity in hemophilia care
9. Management of special bleeds (for example, ileopsoas, renal)
10. Role of arthrocentesis in hemophilia care
11. Management of cardiovascular disease in hemophilia
12. von Willebrand disease and rare bleeding disorders

**TIMELINE**

The initial letter of intent and abbreviated CV are due on February 1, 2017. Shortlisted candidates will be notified in March and invited to submit a full research project by May 15, 2017.

We look forward to receiving your applications. For more information visit www.wfh.org/crgp or email us at crgp@wfh.org.
WFH eLearning Platform showcases lab manual videos

Every year around the world, the WFH provides multiday workshops to train laboratory professionals. Fellows of the International Hemophilia Training Centre (IHTC) Program also receive expert training in laboratory diagnosis. The effectiveness of these in-person learning opportunities—where participants stand right beside an expert, match their movements, and can ask the how and why of every step—cannot be equaled. But what about those laboratory professionals who do not have the opportunity to attend a live training? Or the professional who trained a few years ago, and now needs a little refresher?

In order to give everyone the opportunity to learn from laboratory experts, the WFH has created a number of lab manual videos that demonstrate the three foundational manual techniques of bleeding disorders diagnosis. These videos are available to anyone with an internet connection through the new WFH eLearning Platform.

Improving the diagnosis and treatment of bleeding disorders in developing countries is a WFH strategic objective because accurate diagnosis is key to adequate treatment and management. The WFH Diagnosis of Hemophilia and Other Bleeding Disorders: A Laboratory Manual, written and reviewed by the world’s leading experts in coagulation testing, is the definitive, how-to guide for the accurate diagnosis of hemophilia and other bleeding disorders. But laboratory techniques can be complex and their execution must be nearly perfect in order to obtain accurate results. A written protocol provides important information—but nothing beats watching someone actually do the technique.

Sukesh Nair (outgoing chair of the WFH Laboratory Sciences Committee) and Steve Kitchen (current chair of the Lab Committee) carefully crafted the videos to provide step-by-step demonstrations of the manual execution of the APTT (activated partial thromboplastin time), one-stage FVIII, and FVIII inhibitor assays. Shot from multiple camera angles, the videos provide laboratory professionals with the chance to compare their own method to that of an expert. Each video provides a master class on an important technique, from working several typical patient samples to preparing calibration dilutions to plotting and interpreting results.

The videos also address challenges faced by laboratories operating with significant resource constraints, and they go over practical solutions to help laboratory professionals maximize the accuracy and precision of their diagnostic work. “Addressing the realities of diagnosis in suboptimal situations was key to producing a learning tool that would be really practical and useful,” explained Nair.

Each video is accompanied by the corresponding protocol from the Lab Manual, sample assay record sheets, the graph paper required to plot the results, and a full transcript of the entire text of the video. A keyword search of the transcript highlights each point where that topic is discussed, and with a simple click the viewer can jump to the corresponding spot in the video. This multimedia approach, made possible by the launch of the new WFH eLearning Platform (eLearning.wfh.org), allows Kitchen and Nair to share their wealth of knowledge with laboratory professionals all over the world. Kitchen said of his involvement, “I really enjoy delivering the WFH regional live laboratory trainings in person, but these videos are an opportunity to reach so many more people. Two days spent filming in my lab to make videos that will be seen by far more laboratory professionals than I could ever train in two days is time well spent.”

The videos were launched at the WFH 2016 World Congress in Orlando, and delegates had the opportunity to explore them at the WFH Resource Centre in the exhibit area. “These videos are a great addition to the Lab Manual,” enthused Sheldon Simson, a medical technologist and WFH International Hemophilia Training Centre (IHTC) Fellow from Suriname. “I am looking forward to sharing them with my colleagues in the lab. It’s a handy tool… you can even skip to certain points of interest by typing in a specific phrase. What more could we ask for? I also think that countries who cannot do factor assays yet can get a jump start with this.”

To find out more about the WFH lab manual videos, watch our demonstration video on eLearning.wfh.org.
World Hemophilia Day is a special opportunity for everyone in our community to come together and support those with hemophilia and other inherited bleeding disorders. On April 17, 2017, the tradition of “Lighting it up red” will continue and people in cities around the world will light up major landmarks in red to show support for the global bleeding disorders community. One of the objectives of the “Lighting it up red” campaign is to create visibility for people living with a bleeding disorder so that they know that the WFH and their peers are there for them. The event is also done for those who may not be aware of our community—for those who do not have a diagnosed inherited bleeding disorder. To that group of individuals, “Lighting it up red” is an invitation to find out more about World Hemophilia Day and inherited bleeding disorders. It’s also an opportunity for them to learn about the fact that many people have an inherited bleeding disorders and are not diagnosed, or live with one and don’t have access to care.
Join us on April 17, 2017, and celebrate the bleeding disorders community!

Don’t forget that you can also play a part in lighting it up red this April. If your city is participating in the campaign, take a few minutes to visit the landmark being lit up, take some photos, and share them on our Facebook page or Twitter using #WHD2017.
Recipients double as WFH Humanitarian Aid Program expands

It has only been one year since the expansion of the World Federation of Hemophilia (WFH) Humanitarian Aid Program. In that short period of time, the number of recipient countries has already increased from 58 to 63, while delivered donations reached a landmark of 100 million international units (IU), with over 6,000 people receiving much needed treatment to date. As part of their commitment to donate up to 500 million IUs over five years, shipments of clotting factor concentrates (CFC) from Biogen and Sobi have now been delivered to the areas most in need in developing countries around the world.

“With the expansion of the WFH Humanitarian Aid Program, Senegal has improved accessibility to treatment by providing surgeries for people with hemophilia, establishing a new prophylaxis program for children, and finally helping improve government involvement to ensure the sustainability of the treatment for patients,” said Saliou Diop, MD, Director of the Senegalese National Center of Blood.

The increase of CFCs channelled through the WFH Humanitarian Aid Program means that there has been a significant increase in the number of patients treated globally—from 1,425 in 2015 to more than 4,000 so far in 2016. For the first time with the program, there was also remarkable product utilization reported for prophylaxis treatment, with 897 patients and 10.2 million IUs utilized and reported to date. Product utilization has also been remarkable for surgeries, with 559 surgeries and 4.4 million IUs utilized and reported to date. Of these surgeries, 18% were lifesaving interventions and the rest were able to improve the physical functioning of the patients—with many able to walk after a lifetime confined to a wheelchair.

The lack of access to care and treatment in developing countries is an urgent and important public health challenge, as the cost of treatment is prohibitively expensive for the majority of those affected with a bleeding disorder. Due to the limited access to diagnosis and treatment in many developing countries, people with severe hemophilia in these areas often do not survive to adulthood.

Since the WFH Humanitarian Aid Program was launched in 1996 and before the expansion of the program, over 322 million IUs of CFCs have been distributed to over 90 countries, helping over 100,000 people with hemophilia. For many developing countries, product donations are often the only source of treatment product for patients with hemophilia and other bleeding disorders. The WFH receives requests, many urgent in nature, from our national member organizations (NMOs) and from recognized hemophilia treatment centres (HTCs) around the world.

An increasing number of collaborators in the global bleeding disorders community have accepted the challenge of providing a sustainable and predictable supply of donated products. Through the donation by Biogen and Sobi to the WFH Humanitarian Aid Program of up to 500 million IUs within five years, the three year commitment from Grifols for 20 million IUs per year, the three year agreement with CSL Behring for a total of 10 million IUs, and the agreement with Green Cross for 6 million IUs, there will now be a more predictable and sustainable flow of humanitarian aid donations to the global community. In addition, the continued efforts of the Canadian Blood Services, Biotest, and Grifols with Project Recovery, and the work by the Italian National Blood Services through Project Wish allow for the manufacturing of clotting factor concentrates from previously discarded cryopaste which provide treatment products to countries most in need. These commitments will contribute to the further expansion of the WFH Humanitarian Aid Program.

The expansion of this program has increased the possibility of people with bleeding disorders in the developing world—including young children—having continued access to treatment for emergency situations, acute bleeds, corrective surgeries, and prophylaxis.
New WFH IEQAS pilot initiative

The WFH International External Quality Assessment Scheme (IEQAS) Program recently launched a new pilot project to further assist participating laboratories that continue to have outwith consensus results in their testing. Guidance is already provided to hemophilia treatment centre laboratories by the WFH, UK NEQAS (United Kingdom National External Quality Assessment Service), as well as the IEQAS committee through emails. When a laboratory has already exhausted all options to try to resolve an issue through the usual channels, the WFH can now ask the members of the IEQAS and the Laboratory Sciences committees to provide assistance by conducting a site visit of the laboratory.

He travelled to Africa and spent two days in December 2015, and one day in February 2016, working with the laboratory staff, trying to find solutions for their FVIII and FIX issues. The UK NEQAS sent the African lab repeat samples to work with. After the visits, Toulon provided recommendations to the centre and wrote a report to the WFH detailing his findings. He also shared his experiences and findings with this new initiative at the WFH 2016 World Congress in Orlando in July 2016 during the IEQAS participants’ session.

There are current plans to conduct a laboratory site visit in the Americas and in Europe. The WFH and the IEQAS committee will continue to identify participating centres that would be good candidates for this exciting new initiative. The WFH is always trying to collaborate with hemophilia treatment centres to help improve their laboratory testing and diagnosis practices through the IEQAS Program, as it continues to show great promise for treatment centres around the world.

The IEQAS Program is supported by funding from the Novo Nordisk Haemophilia Foundation.

GAP program in Vietnam

On September 21, 2016, in Thanh Hóa, Vietnam, a Memorandum of Understanding was signed by the Ministry of Health of the Socialist Republic of Vietnam – National Institute of Hematology and Blood Transfusion and the World Federation of Hemophilia (WFH) for the implementation of a Global Alliance for Progress (GAP) Program from 2016 to 2019.

Program relationship was established between the National Institute of Hematology and Blood Transfusion (NIHBT) and the Alfred hospital, Australia. The Australian HTC helped advance care by creating an NIHBT comprehensive care team to serve patients from Hanoi and the northern provinces. The program also helped raise the level of hemophilia awareness and knowledge for healthcare providers around the country.

That same year, the WFH supported the Vietnam Hemophilia Association (VHA) by facilitating a hemophilia organization Twinning Program partnership with the Irish Haemophilia Society. Today, the VHA is an active organization with three regional branches, four chapters, and three less structured groups.

The GAP program in Vietnam will establish a national hemophilia care program with a national registry supported by the Ministry of Health. This will also help to expand the care services of the network of seven HTCs in Hanoi, Ho Chi Minh City, Hue, and Can Tho through staff training. In addition, ten satellite HTCs and ten VHA chapters will help provide basic care, help procure factor concentrates through a national tender, and reduce state insurance co-payments for factor concentrates.

Ultimately, the GAP Program in Vietnam is not just about helping bleeding disorders patients with medical aid—it is also about encouraging and motivating them to take on greater leadership roles and become more active in the Vietnamese patient association.

The GAP Program is supported by funding from: Bayer, Biogen, Biotest, CSL Behring, Grifols, Kedrion, Novo Nordisk, Pfizer, Shire, and SOBI.
One global organization, many ways to give

The World Federation of Hemophilia (WFH) is an organization built on the generosity of people who are willing to give in the name of advancing the vision of Treatment for All. Many people share their time and talent with us, while a growing number support us financially. We are excited to introduce two people involved with the WFH who we believe truly capture the spirit of giving: Jim Munn and Genevieve Beauregard. Here are their stories.

/ Roddy Doucet, MANAGER, MAJOR GIFTS

JIM MUNN

Jim Munn works with the Hemophilia and Coagulation Disorders Program at the University of Michigan Health System in Ann Arbor, Michigan, and recently completed two terms as the Co-Chair of the WFH Multidisciplinary Committee. He attended his first WFH meeting in 1998 and became a member of the WFH Nurses Committee at the end of the 2008 Istanbul World Congress. Munn’s motivation to transition into a leadership role is one many in the global bleeding disorders community will be familiar with: he drew inspiration from the work of another volunteer. In his case, that person was Regina Butler, Registered Nurse from the Children’s Hospital of Philadelphia. Already at the point of volunteering with the National Hemophilia Foundation (NHF), Munn succinctly describes his state of mind after hearing Regina’s presentation as, “I was hooked.”

He has many experiences as a volunteer that made strong impressions on him. He recalls traveling with the WFH as a volunteer to attend nursing training workshops in Kenya and Mongolia, and seeing the local families travelling long distances to meet with the nurses so they could practice recording family history information. To his shock, Munn learned that in every family history there was at least one death due to complications related to hemophilia, many coming at a very young age. Yet, within this sadness he also found joy as every patient and family member they met were so grateful for the opportunity to share their stories and know they were contributing to a more certain future for their loved ones.

Faced with this tremendous uncertainty over access to medication, Munn, in awe related, “Remarkably, they have been able to provide their son with almost uninterrupted weekly prophylaxis for the past two years.”

Munn encourages people to get involved and share with the WFH. He believes that giving back has a strong impact on lives you touch—as well as your own.

GENEVIEVE BEAUREGARD

Genevieve Beauregard is intimately aware of the difference giving can make in the lives of those living with a bleeding disorder. Beauregard has a decade-plus history of involvement with the Canadian bleeding disorder community. Beginning in 2004, she worked with the Canadian Hemophilia Society’s Quebec chapter, launching a fundraising event for them in 2006 entitled “Dance for Life”. She understood early on that there was a need for on-the-ground help in many developing countries. However, it was a 2013 visit to Nicaragua that really had a deep impact on her. On this trip, Beauregard was the Quebec delegate for a WFH Twinning Program. This program aims to have organizations or hemophilia treatment centers (HTCs) from developed countries work together with developing countries to share information and transfer expertise, experience, skills, and resources. What she witnessed motivated her to action. She recalled thinking that, “In a country a short five-hour flight away from Montreal, there were individuals in dire living conditions with no access to care, limited access to doctors, nurses, and physiotherapists... in short, everything we have in abundance in Canada.”

Upon her return from Nicaragua, she immediately began supporting the WFH with a monthly donation. She believes that every donation makes a difference. Monthly donors provide a stable source of funding for the WFH—one that will give us the financial flexibility to take advantage of new opportunities as they arise.

Beauregard and Munn are part of the growing list of people who have made a difference by choosing to get involved in meaningful ways with the WFH. We are grateful to everybody, past and present, who have chosen to join us as we pursue our shared vision of Treatment for All.
2015 WHF Annual Global Survey now available

The Report on the Annual Global Survey 2015 is now available in print and online at www.wfh.org/globalsurvey.

/Christine Herr, DATA AND RESEARCH COORDINATOR

The report includes selected demographic and treatment-related data on people throughout the world with hemophilia, von Willebrand disease (VWD), other rare factor deficiencies, and inherited platelet disorders. Its objective is to provide hemophilia organizations, hemophilia treatment centres (HTC), and government health officials with useful information to support efforts to improve or sustain the care of people with bleeding disorders, and to assist with program planning. This year’s report includes data from 111 countries, representing 91 percent of the world population.

The look and feel of the report has been completely redesigned this year in order to make it even easier to read, absorb, and understand the wealth of data found in its pages. The WFH is also making supplementary charts and graphs available online to anyone who wants to get even more information about the world of bleeding orders today.

As of 2015, the total number of people identified with bleeding disorders is 304,362. Of that total, 187,183 people were identified with hemophilia, 74,819 people were identified with von Willebrand disease, and 42,360 people were identified with other bleeding disorders. Compared to the findings from the 2014 report, that’s an increase of 17,296 people identified with bleeding disorders.

Encouragingly, 90 countries submitted data for 2015—a ten percent increase from the previous year. Since not all WFH national member organizations (NMOs) are able to report every year, historical data is used to supplement the Annual Global Survey. Fortunately, the high response from our NMOs allowed us to reduce the amount of historical data needed to only one year.

The WFH would like to thank all of our NMOs for participating in the 2015 Annual Global Survey and for contributing to our global data collection efforts. The Report on the Annual Global Survey 2015 was developed under the supervision of the WFH Data & Demographics Committee.

For more information about the Annual Global Survey, please contact globalsurvey@wfh.org.
Philanthropy at the WFH

The dictionary defines philanthropy as the desire to promote the welfare of others. The WFH Philanthropy Resource Department (PRD) strongly believes that our organization embodies this in everything we do, from workshops for healthcare professionals to the expanding WFH Humanitarian Aid Program.

/ Roddy Doucet, MANAGER, MAJOR GIFTS

Paula Curtis, the Director of the PRD department, believes that the three pillars of Connection, Community, and Culture will form the basis of the department’s success in the coming years. She notes, “Every time I visit with a supporter, meet a patient or attend an event like the WFH 2016 World Congress, I see people from all over the world connecting with each other, developing bonds that transcend borders to form a truly global community.” Building on this inspiration, the PRD team is setting out to develop a truly reciprocal philanthropic culture that engages us all in a collaborative and supportive way, regardless of how we support the WFH vision of Treatment for All.

This approach is made possible through collaborative work—and an excellent example of that is when WFH USA worked with the National Hemophilia Foundation (NHF) to launch the NHF Chapter Challenge, held in advance of the WFH 2016 World Congress in Orlando, Florida. For the first time, the PRD team engaged local chapters from the Atlantic to the Pacific. So far, we have raised approximately $200,000 for the WFH Humanitarian Aid Program. This is proof of how we can produce life-changing results by working together.

The willingness of our community to give back in so many ways makes our story one that resonates powerfully in our community. Indeed, the fact that so many of you choose to give back to your community through donating your time, sharing your talents and supporting our work financially sends a strong message to our organizational, corporate and individual donors. The PRD team thanks all of you for your support and we look forward to working with you to bring a better quality of life to those living with a bleeding disorder, no matter where they live.

Paula and the entire team encourage you to volunteer with your national patient organization or consider supporting WFH at www.wfh.org/donate.

Cornerstone Initiative launched in Zambia

In September 2016, the World Federation of Hemophilia (WFH) and the Hemophilia Foundation of Zambia (HFZ) organized two training workshops for lab technicians and physiotherapists, representing all 10 provinces from across Zambia.

/ Rana Saifi, REGIONAL PROGRAM MANAGER, MIDDLE EAST & AFRICA

Both workshops were held as part of the Cornerstone Initiative supported and funded by the WFH. The Cornerstone Initiative program in Zambia will help facilitate the transfer of knowledge and expertise, and it will help train patients and healthcare professionals in the country. The objective is to reach the most vulnerable members of the country’s bleeding disorders community.

The training workshops were hosted at the University Teaching Hospital in Lusaka. The aim of the workshops was to introduce laboratory technicians and physiotherapists to the basic concepts and principles of hemophilia care. The workshops also included specialized training on the challenges lab technicians face when performing a diagnosis or measuring clotting factor and inhibitors. The principles of physiotherapy management of hemophilia and associated risks and complications for physiotherapists were also covered.

The training was about more than just disseminating theoretical information—both workshops included practical, hands-on sessions aimed at immersing participants in the experience of working on both lab tests and patient care. Participants also received copies ofWFH training and education materials to help them better incorporate WFH standards of diagnosis, care and treatment into their daily work.

The workshops were a great opportunity for the HFZ to continue to engage with high level officials to help solidify their advocacy efforts. So far, the HFZ and the WFH have been able to get the full support of the First Lady of Zambia, Esther Lungu, and Zambia’s Minister of Health, Chilatu Chilufya, MD. This political support is the result of the HFZ being very active since it was established in 2012; it joined the WFH in 2014 and became involved with the WFH Cornerstone Initiative Program in 2015. Charity Pikiti, Chairperson of the HFZ, said, “We are deeply grateful to the WFH for their professional work and selfless efforts. We are confident that after conducting the training, the knowledge gained by lab technicians outside of Lusaka will ensure that patients we identify through our outreach work can be verified through accurate diagnosis. We now also have a network of trained physiotherapists who can work with identified patients to help ensure a better quality of life for them.”

“This was a wonderful opportunity to learn and engage with my fellow physiotherapists from across Zambia. We are now better placed to pass on the knowledge about hemophilia to others to help increase awareness and ensure that the patients are better cared for.”

—Esther Shakachite, Physiotherapist, Mansa General Hospital, Luapula province.
Thank You
To the sponsors and supporters who have committed to contributing to the mission of Treatment for All.

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Biogen
Biotest
Grifols
Kedrion
Novo Nordisk
Pfizer
SOBI

SPONSORED PROGRAMS
Twinning Program
Pfizer
International External Quality Assessment Scheme Program
Novo Nordisk Haemophilia Foundation
International Hemophilia Training Centre Fellowship Program
Bayer
WFH Research Program
Bayer
Grifols
Hemophilia Center of Western Pennsylvania 340B Program
Shire
WFH eLearning Centres:
Visionary Sponsor
Shire
Supporting Sponsor
Inhibitor: F. Hoffmann-La Roche Ltd, Shire
Website localization projects:
Arabic: Pfizer
Japanese: Biogen
Russian: SOBI
Simplified Chinese: Bayer
WFH Humanitarian Aid Program
Bayer
Biogen-SOBI
Biotest
CSL Behring
Grifols
Octapharma
Precision BioLogic
Shire

Other sponsored programs
Data Collection and Use of Data in Bleeding Disorders Training Workshop: Shire
Inga Marie Nilsson Award:
Octapharma
Susan Skinner Memorial Fund:
Hemophilia Alliance Foundation von Willebrand Disease Workshop: LFB
Youth Leadership Development Workshop: F. Hoffmann-La Roche Ltd
World Hemophilia Day
Bayer, CSL Behring, F. Hoffmann-La Roche Ltd, Novo Nordisk, Precision BioLogic, SOBI

HEMOPHILIA WORLD WOULD LIKE TO HEAR FROM YOU!
The activities of people living with hemophilia and other inherited bleeding disorders, and their organizations, are important to everyone in the global bleeding disorders community. We welcome stories, letters, and suggestions for articles. Please send them to:
Michel Semienchuk, Editor
Hemophilia World
Fédération mondiale de l’hémophilie
1425, boul. René-Lévesque Ouest, bureau 1010
Montréal, Québec H3G 1T7 Canada
E-mail: msemiencuk@wfh.org

Calendar of events
10th Annual Congress of EAHAD
February 1-3, 2017
Paris, France
eahad.org/eahad-2017

IPFA 2nd Asia Workshop on Plasma Quality and Supply
March 2-3, 2017
Yogyakarta, Indonesia
Tel.: +31 20 512 3561
Email: info@ipfa.nl
www.ipfa.nl/events

Spanish Hematology Meeting
April 20-21, 2017
Buenos Aires, Argentina
www.acamedbai.org.ar/iihema.php

WFH 15th International Musculoskeletal Congress
May 5-7, 2017
Seoul, Republic of Korea
www.wfh.org/en/msk
msk2017@wfh.org

IPFA/PEI 24th International Workshop on Surveillance and Screening of Blood-borne Pathogens
May 16-17, 2017
Zagreb, Croatia
Tel.: +31 20 512 3561
Email: info@ipfa.nl
www.ipfa.nl/events

ISTH 2017 Congress
July 8 - 13, 2017
Berlin, Germany
www.isth2017.org

National Hemophilia Foundation (NHF)
69th Annual Meeting
August 24-26, 2017
Chicago, Illinois
www.hemophilia.org

IPFA/BCA 3rd Global Symposium on the Future for Blood and Plasma Donations
September 11-12, 2017
Atlanta, GA, USA
Email: info@ipfa.nl
www.ipfa.nl/events

10th WFH Global Forum on Research and Treatment Products for Bleeding Disorders
November 8-10, 2017
Montreal, Canada
gf@wfh.org
HEAR THEIR VOICES

On World Hemophilia Day let’s come together to show our support for the millions of women and girls affected by bleeding disorders.