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OJHM

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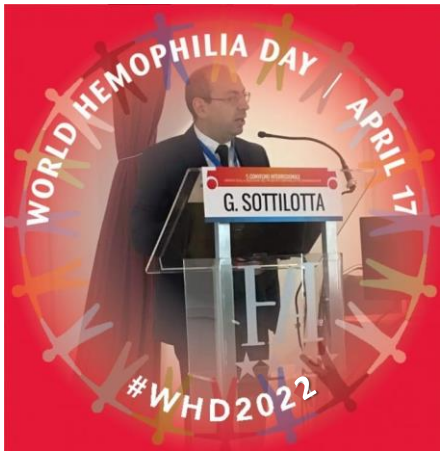
Aims and scope

ONLINE JOURNAL OF HEMATOLOGY AND MEDICINE (OJHM) is an interdisciplinary open access online journal focusing primarily on blood diseases. The journal publishes original contributions in non-malignant and malignant hematological diseases. It also covers all the areas related to the hematological field that takes care of diagnosis and treatment of blood disease. Particular editorial interest is addressed to: Inherited and Acquired Clotting Disorders, Antiphospholipid Syndrome, Clinical Management of Bleeding Diseases, Coagulopathies, Hemophilia, Platelets Disorders, Thrombotic Disorders. Manuscripts should be presented in the form of original articles, editorials, reviews, short communications, or cases report, all submissions are rigorously peer reviewed.

All manuscripts submitted to OJHM must be previously unpublished and may not be considered for publication elsewhere at any time during OJHM's review period.



APRIL 17
2022

WORLD HEMOPHILIA DAY

#WHD2022

WORLD HEMOPHILIA DAY

The idea of creating a special issue of OJHM for the World Hemophilia Day, came from the real purpose of this anniversary: to give visibility, to share scientific and social information, to increase knowledge about hemophilia and the other rare bleeding diseases. For this reason, the editorial staff wanted this time to change the typology of the magazine and of the articles: they are focused not on scientific research, or on the description of medical and therapeutic experiences, or on clinical cases, but on the activities of the associations of patients with hemophilia. These national and local associations carry out constant information activities, social assistance and sometimes support for hospitals and centres for the treatment of haemophilia all over the world, with the aim of improving medical care for hemophilia patients, guaranteeing access to care and helping patients and their families to escape from anonymity. This is done every day with group meetings between patients or between doctors and patients, between manufacturers of hemophilia drugs and families, always with the aim of introducing hemophilic children and their parents to each other, making them understand that they are not alone, that being hemophilic is not a shame, that the future of people with hemophilia must be the same as that of their peers without hemophilia. Each in their own social, economic and cultural reality but with a single goal: to improve knowledge of hemophilia and achieve equal access to treatments, even the most modern. Good World Hemophilia Day to everyone.

Dr. Gianluca Sottilotta, MD
OJHM Editor

Cesar A. Garrido

President of the World Hemophilia Association

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Inviting to celebrate

The sentence “I invite you to celebrate” had not been so pertinent during the 2 years prior to this April 17, 2022. COVID-19 has kept us sad, worried, and busy. It is only now that we are beginning to see that we have almost defeated this enemy of health, which has kept us isolated and unable to carry out many of the activities that we have been accustomed to carrying out, as part of the lives of people with hemophilia or other coagulation disorders. So, as we have risen victorious and re-empowered, when after having suffered the dramatic impact of HIV and Hepatitis C, which had snuffed out the lives of many in our community in the 1980s and 1990s, we must now react with much greater courage, strength, experience, knowledge, and optimism. During these 2 years, our World Federation of Hemophilia has maintained contact with its 147 national member organizations, in most cases virtually, adapting to schedules that allow more than 100 webinars on various topics to keep us up-to-date on everything which the new innovative therapies and medicines are offering us. We have had to carry out evaluations of different NMOs, subcontracting local professionals in different countries that would allow us to interrupt our usual evaluation as little as possible. After involving all the stakeholders of our WFH and more than 200 volunteers on the topics of social leadership or health care, we were able to design a strategic plan for 5 years until 2025, which would allow us to modernize, adapt to new challenges, to have a greater presence throughout the world, to be able to educate and train, on expected and really necessary topics, that help us achieve the vision of "Treatment for All". We were able to launch the 3rd edition of the WFH treatment guides to the world, with the task of translating them into as many languages as possible in our community, with the aim of reaching everyone. We were able to successfully continue our Humanitarian Aid program, covering more than 21,000 patients in 2021, in countries where it was almost impossible for these people to receive treatment. For this to happen, extra work was needed from our staff and especially from the Department of Humanitarian Aid, seeking to overcome the significant obstacles that caused, in terms of logistics and permits, the closure of borders in many recipient countries. Now that we have reached April 17, 2022, we can look to the future by focusing on rapidly reducing the inequity in appropriate treatment for our patients, when almost 70% of those diagnosed and registered do not have the appropriate treatment or they have no treatment at all. This year, our central theme in celebrating World Hemophilia Day is "ACCESS FOR ALL" and for this, we consider 3 key words in the strategy that will allow us to make it possible to achieve that deserved access for all. These words are Partnership, Policy, and Progress.

Only by working in an associated, organized, and continuous way, will our health professionals, hand in hand with the leaders of patient organizations, be able to influence health policies and involve decision makers, in each of the governments in our respective countries and thus we can have progress in the face of the enormous challenge of "ACCES FOR ALL"

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SUPPORTING EDUCATION IN CHILDREN AND ADOLESCENTS WITH HEMOPHILIA: THE EXPERIENCE OF SAVE ONE LIFE

On February 21, 2022, Dr. Paul Farmer, founder of Partners in Health, died unexpectedly in Rwanda at age 62. He was an extraordinary visionary, leader, physician and humanitarian. He was my hero and role model. Originally from western Massachusetts, like me, he attended Harvard University and became an internationally renowned infectious disease expert. He counted Bill Gates and Bono as colleagues and friends, as well as the poor of Haiti. He helped rebuild Rwanda's healthcare system following the genocide, and decided to live there. And he created the best hospital in Haiti, revolutionary in concept, which excels today in its service to the poor. Save One Life, the nonprofit I founded, also serves the world's poor. We had just partnered two years ago with Farmer's hospital, Hôpital Universitaire de Mirebalais, to bring the first ever hemophilia program to Haiti. For Paul Farmer believed, as we do, that every life counts, and every person deserves healthcare. Ironically, the seeds for Save One Life were sown during the Rwandan genocide. I had just given birth to my third child in March 1994, and had just watched the movie "Schindler's List," which ends powerfully with Oskar Schindler receiving a ring from the Jews he saved, inscribed with "He who saves one life, saves the world." That phrase, both from the Talmud and the Koran, never left me. Schindler had always said, "Just one more... just one more," as he saved Jew after Jew from certain death. I grieved for the Rwandans, as I am sure Farmer did, and only wanted to adopt an orphan. Just one. I felt so powerless to help; perhaps saving one child would ease my suffering and give a new life to a baby who lost its family. I was not able to adopt the Rwanda orphan I so badly wanted, but I eventually founded Save One Life so that people like me – a regular mother of a child with hemophilia – could try to save

one life: a child with hemophilia in a foreign land, where no treatment existed. It was a way to show gratitude for all the life-saving medicine to which my child had access. It was also a daunting task, requiring days, months, years of my life, and a lot of money, to get it off the ground. It had not been done before in hemophilia. But this idea - that we can focus our help on one person - touched others in the US hemophilia community, and made them feel more empowered to do something to help. One person in a developed country, with access to factor, could indeed directly help another, one-to-one. To know a child's name, his birthday, his family; to be able to give him money to help him go to school, or have nutritious food, or wear better clothing. We would give them that bridge, that conduit. It was beneficial that I had founded a publishing company in 1990 focusing on hemophilia; I had literally thousands of US families in my database. And pharmaceutical representatives and CEOs, and specialty pharmacies and HTCs. Thousands. I reached out and the response was amazing. We collected unwanted factor; we signed up people to sponsor children in India, Nepal and Pakistan, our first countries. I traveled to these countries to form bonds with the national organizations, which gladly worked side by side with us to make Save One Life successful. Children received funds and factor. They went back to school

They stopped the bleeds. As I traveled, I saw more needs. Most countries did not have hemophilia camps, so vital for socialization and community. So we established camps in several countries, and helped fund others that were established but in need. As our children aged and graduated, another problem arose. What about college? They lacked the funds. We started the first international hemophilia scholarship fund. These children were now young adults, and many went to college. We have graduates who even became hematologists! Others, not inclined to study, wanted income to support themselves. Another idea crystallized: micro-enterprise grants, to give them a start in the business world. We were amazed when applications came in for cell phone repair shops, roadside vegetable stalls, taxi and auto-rickshaw businesses, sewing machines, and even cows, to sell milk to local villagers. And all the while we knew every single person's name, date of birth, address, and family members. My favorite part of Save One Life has always been visiting families in their homes. Accompanied by our program partners, we've been to stifling slums in Mumbai and Nairobi; to dusty villages deep in Africa; to steel-roofed homes in the hamlets of Haiti; to squatters' make-shift homes in Nicaragua. We sit with the families, share their meals, ask them about their lives. We record their stories to bring back with us. We want the haves to know how the have-nots with hemophilia live. If we can reach people's hearts through compassion, we can compel them to act too. And we can compel them to act if they believe they will make a difference. Sometimes, the overwhelming numbers - 300,000 worldwide in need of factor, 95,000 Rwandan orphans - paralyze us. What difference could one person possibly make? But knowing a child's name and face, and a secure way to get them funding directly, makes us feel we can change that life, and change the world.

Save One Life just celebrated its 20th anniversary in 2021. Each of those individual lives add up:
- We now work in 14 developing countries, with 45 program partners.
- We have sponsored over 2,000 children individually
- We currently sponsor 1,400 children through 800 sponsors
- Since 2012, we've provided 378 scholarships to 214 students in 10 countries.
- Since 2014, we've awarded micro-enterprise grants to 183 patients in 13 countries.
- Since 2002, we've shipped an estimated $200 million worth of factor to 78 countries.

We've been the first to visit and assess the hemophilia situation in over a dozen developing countries, and have helped to start hemophilia organizations there. Rwanda and Haiti were among our latest; something, I think, the intrepid Dr. Paul Farmer would have approved. Save One Life, I hope, compliments the current global model of hemophilia care, which is top-down: from the developed countries, factor and training goes to the health ministries and clinics, and the national organizations. We start at rock bottom, with the neediest and poorest, to assess their needs, find community leaders, and empower them. We match sponsors with a child in need. And we build from there. We apply a holistic approach: direct financial aid; registration with the national organization; factor to stop bleeds; cooperation with the medical community.

Attendance at camp; a scholarship to attend college, or a micro-enterprise grant to start a small business. We support the needs of the family as a a whole, not just treat the bleeds. Farmer once quoted a Haitian axiom: "Giving people medicine... and not giving them food is like washing your hands and drying them in the dirt." Of course, we love big numbers too. Who wouldn't want to say that they had helped thousands and thousands lives? Yet, to capture the hearts, imagination and actions of the masses, we believe we need to focus on the one. Paul Farmer also said, "If I saved one patient in my whole life, that wouldn't be too bad." Paul Farmer believed in helping one at a time, in visiting patients where they lived, in revolutionizing healthcare by going against conventional wisdom, and he believed in action. Action with compassion. I hope we keep his indomitable spirit, embodied in the work by Save One Life, alive. In Rwanda, in Haiti, and in every single child with hemophilia in need.

Laureen A. Kelley is founder and president of LA Kelley Communications, Inc., a publishing company for educational books on bleeding disorders, and Save One Life, Inc., an international nonprofit that gives direct financial aid to families with bleeding disorders. She is also author of 11 books on bleeding disorders, including the first book ever on von Willebrand disease. Until 2021, she published the longest-running newsletter on hemophilia in the US, and still publishes HemaBlog, the first dedicated blog on hemophilia, since 2006.

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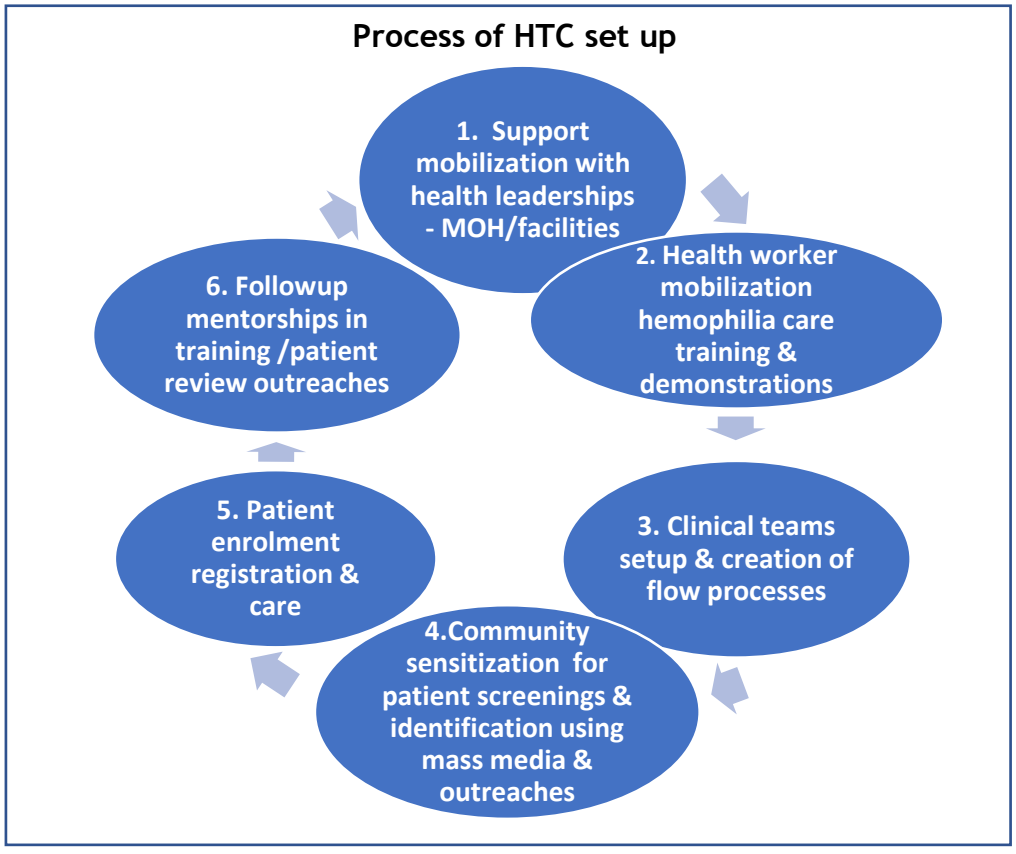
PROCESSES AND EXPERIENCES OF SATELLITE HEMOPHILIA CLINIC SETUPS IN UGANDA

Introduction

Hemophilia knowledge and care are largely missing in much of Africa's Sub-Saharan population and health care setting. Previously thought to be limited among persons of European descent, the disease is increasingly being diagnosed among Africans. Hence the need for concerted efforts to ensure access to care services by affected persons. Hemophilia Foundation Uganda with support from the global haemophilia community has awakened mobilization for awareness and care working with the Uganda Ministry of Health. To date eight Hemophilia Treatment Centres (HTCs) have been set up at eight large public health facilities across Uganda including; Masaka, Mbale, Mbarara, Nakivale, Lira, Gulu, Lacor, and Nebbi hospitals. We share the processes, experiences, and future goals.

Experiences

We observed great interest in hemophilia knowledge among the health staff who attended the training in high numbers at each of the above 8 centres. The majority (> 95%) had never cared for a patient with hemophilia. Care teams were created, which has increased the patient population. Over 1700 Health care professionals have been trained and 121 patients enrolled at these peripheral facilities in the past 5 years (54 Western, 11 Southern, 14 West Nile, 30 Eastern, 12 Central (greater Masaka), and 65 Northern regions of Uganda).



Shortcomings

These include limited diagnostics capacity for haemophilia (inability to perform coagulation tests and factors assays) and personnel for allocation to haemophilia treatment who also have a high workload. We also appreciated the limited capacity for the facilities to procure recombinant factors related to budgetary constraints.

Future goals

Further advocacy for budgetary inclusion of haemophilia at political and facility levels. We also propose a continued strengthening of the Hemophilia care teams through mentorships, networking, and mobilization for diagnostic support at large public hospitals.

HCP training at Nebbi Regional Referral Hospital, West Nile region, the training was facilitated by Dr. Philip Kasirye Gitah

HAEMOPHILIA FOUNDATION OF UGANDA

Daniele Preti
Cristina Cassone
Federazione delle Associazioni Emofilici, Italia

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FEDEMO SPORT: DEFINITION OF A MODEL MEDICAL CERTIFICATE OF FITNESS FOR COMPETITIVE SPORTS FOR PEOPLE WITH HEMOPHILIA AND OTHER CONGENITAL BLEEDING DISORDERS

The subject of physical activity and sport in persons with hemophilia has always been of great interest for FedEmo. Over time FedEmo has organized several projects in this area. The FORTE project, for example, was addressed to training a significant number of physiotherapists from the whole national territory, in order to encourage hemophilic patients to do a constant physical activity through specific exercises dedicated to them. Or the Maratona project, thanks to which, after a preliminary and tight monitoring of their clinical conditions and an appropriate period of physical training, a significant group of hemophiliacs patients (some of them with one or more joint replacements) successfully ran the New York Marathon in 2015. In this context, the FedEmo Sport project was born with the purpose to widen the range of possible recipients and the goal to establish accredited guidelines about physical and sport activity (also at competitive levels) for all the people with hemophilia or other congenital bleeding disorders (MEC). FedEmo Sport - a project which involves representatives of the Italian Association of Hemophilia Centers of Care (AICE), Italian Federation of Sport Medicine (FMSI) and Italian national Olympic Committee (CONI) – starting from a careful examination of the physical conditions of the individual patient (especially his/her joint function), is focused on the analysis of which treatment is most indicated for doing sport safely in a specific person with a congenital bleeding disease and what types of sporting activities are more appropriate for him or her. The project executive Board works to produce a vademecum to be useful for hematologists in recommending a certain kind of sport to a person with hemophilia and to serve as a reference for sport physicians and sports clubs.

The vademecum will contain several sections:

- Introduction to Hemophilia
- Principles of treatment
- Primary, secondary, tertiary and intermittent prophylaxis
- Factor VIII and Factor IX dosage
- Additional therapies
- Possible complications
- Presence of inhibitors
- Specific complications for von Willebrand disease and other rare forms of bleeding diseases
- Benefits of physical activity in people with MEC
- Review of clinical studies

The final step in the project will be the definition of a model medical certificate of fitness for competitive sports for people with hemophilia and other MEC, considering that now these persons, also if therapeutically optimally treated, are often barred from access to a large part of sports disciplines, solely on the basis of their hemophilia condition, without any real physical problem.

FedEmo
Federazione delle Associazioni EMOFILICI

The Italian Federation of Hemophiliac Associations (FedEmo) is a national body which brings together the 31 local associations active in providing support to MEC patients and their families throughout the country. FedEmo represents the interests of more than 10,000 Italian patients with hemophilia and other MEC.
More details about Association, projects and activities are available at: www.fedemo.it

Chimène Vignon
Association Béninoise des Hémophiles
Benin

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RAISING AWARENESS IN BENIN SCHOOLS

In Benin, hemophilia is a pathology still very little known by both health workers and the general population. Knowing that the prevalence of hemophilia in the general population is approximately 1/10,000 inhabitants, the number of hemophiliacs in Benin should be approximately 1149 but in 2020, only 48 hemophiliacs were registered in Benin. However, our culture requires that all young boys be systematically circumcised. This practice is often carried out without any medical precautions at home, either by traditional healers or nurses not authorized for this act. Thus, it is in this context that hemorrhagic complications sometimes arise, sometimes persistent in some children, which can sometimes lead to death. For children with a hemorrhagic syndrome and whose parents have the financial means to take them to hospital, a transfusion of fresh frozen plasma is carried out urgently on these children to help stop the bleeding and to prevent anemia often as a result of the hemorrhage.

Only those who manage to reach the National University Hospital Center of Cotonou can sometimes benefit from the injections of anti-hemophilic drugs offered by the World Federation of Hemophilia when these are available. However, in this hospital, all the patients who consult for a hemorrhagic syndrome do not succeed in benefiting from the adequate treatment because all the costs are covered, in particular the consultation, the biological examination and the care. However, there are many children whose parents do not have the financial means to pay these laboratory examination costs, in particular the dosage of factor VIII and/or IX and that of Willebrand factor. Finally, for the same reasons of lack of financial means, there are many Beninese hemophiliacs who are very poorly followed because they do not have the means to pay the costs of systematic consultations and therefore consult only in the event of a potentially fatal haemorrhagic syndrome. This situation means that a certain number of several hemarthroses are often poorly treated at home. The Association Béninoise des Hémophiles, which I have had the honor to direct since its creation in December 2015 with the support of the Hematology Department of the CNHU of Cotonou, directed by Professor Dorothée Kindé Gazard, former Minister of Health. She brings us a lot of her dedication as well as her expertise; among the many activities that we organize within our community, I would like to talk to you about raising awareness in schools, the case of the Hamadiya school in Parakou.

Raising awareness is one of the means by which we manage to reach the population to share information on bleeding diseases and the methods to adopt to live and carry out treatment with the pathology of hemophilia. In accordance with the pre-established program, we, the members of the Board of the Benin Association of Hemophiliacs, met the students of the Hamadiya school and the teaching staff. Hamadiya School is a private primary school located in Parakou department of Borgou which has 305 pupils. We had raised awareness on December 08, 2021 for a period of one hour. We defined the disease of hemophilia, explained the manifestations and the consequences which it can lead to, it if we do not follow the treatment properly. We also explained the steps of the association in this fight in Benin to receive benefits from other associations, in particular from the WFH, which supplies us with a lot for treatment for everybody, and at the end of the session we taught the methods to adopt for a better grasp of the pathology We also made teachers aware of the consequences of corporal punishment on a hemophiliac in schools. At the end of our presentation, the students and teachers asked a lot of questions about hemophilia and its care, which showed us that the message had got through and that our objectives have now been achieved at the Hamadiya school in Parakou, the students and the teachers are no longer ignorant about the disease of hemophilia and have promised to relay the information around it to their respective families. We members of the ABH came out satisfied with this awareness session in order to continue our awareness adventure in another school, always with the purpose of popularizing the hemophilic pathology and making its existence known, and that it is not a spiritual disease as we say in our country.

Jonathan Gauci

Malta Bleeding Disorders Society

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ACTIVITIES OF THE MALTA BLEEDING DISORDERS SOCIETY: THE IMPORTANCE OF EDUCATIONAL WORKSHOPS

The Malta Bleeding Disorders Society (MBDS) is a non-profit, autonomous, voluntary organisation founded on Saturday 2nd March 2019 in order to represent people with Haemophilia and other bleeding disorders in Malta. The MBDS has since obtained membership of the European Haemophilia Consortium and associate membership of the World Federation of Haemophilia. The MBDS organised its first educational workshop at the Salini Resort in Bahar ic-Caghaq, Malta. The event was opened by our medical advisor Prof Alexander Gatt, expert in Coagulation Medicine, Associate Professor and Head of Department of Pathology at the University of Malta. Our first speaker was Ms Chanel Cassar, who

delivered a presentation on Awareness Campaigns. Ms Cassar spoke about the importance of raising awareness on the symptoms and signs of bleeding disorders, both among healthcare professionals and lay people. The subject of bleeding disorders in women of child-bearing age was also discussed. Our international guest speaker was Prof Albert Farrugia, Professor at the University of Western Australia, and Advisor for the European Haemophilia Consortium and for the Associazione Emofilici di Toscana. Prof Farrugia delved into the history of Haemophilia and the use of clotting factor concentrates. He then explained the new and emerging treatments in Haemophilia, by highlighting the mechanism of action, advantages and disadvantages of extended half-life agents, non-factor agents and gene therapy. The talk was followed by a discussion on the way forward for MBDS as regards the application for the procurement of newer therapies in Malta.

Following this educational workshop, the MBDS members renewed friendships over dinner. Not only did this social event manage to increase knowledge on Haemophilia and other bleeding disorders, but it also served to build a sense of community among people with bleeding disorders and their families in Malta. The MBDS aims to organise several other educational workshops for its members. We are currently looking forward to our outreach event in the city of Valletta for the occasion of World Haemophilia Day 2022.

MBDS MALTA BLEEDING DISORDERS SOCIETY

Tania Mariz Onzi Pietrobelli

Federação Brasileira de Hemofilia

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DEVELOPING TECHNOLOGICAL INSTRUMENTS FOR COMPLIANCE TO HEMOPHILIA TREATMENT IN BRASIL: THE TUGUY APP

Today, technology is present in everything around us and, based on this, the Brazilian Federation of Hemophilia (FBH, initials in portuguese) has cultivated an old desire of several years back: to offer an innovative technology to contribute to the adherence of hemophilia patients to prophylactic treatment. The dream began to materialize with the development of the Tuguy app (a word that means “blood” in the Guarani-Kaiowá language – an indigenous tribe from Brazil). The idea for creating the app started to germinate in 2018 when the president of FBH, Tania Maria Onzi Pietrobelli, started a movement in search of a technology that would bring the patient closer to the HTC, offering care at a distance, since Brazil has continental dimensions.Through the Tuguy, patients can record the bleeding they have had, record the infusions in the Infusion Diary and activate, when necessary, the emergency button and receive professional support through the app. The objective is to promote self-care among patients through a conversation with Tuguy, which reminds the patient the day of his infusion. There is also the possibility for the patient to report bleeding by audio, photo or video. And, with this data sent by the tool, healthcare professionals have real-time access to the information recorded by the patients themselves. With these records, patients can keep their treatment updated.

The president of FBH, Tania, was searching to fulfill her dream of monitoring patients so that she could help carry out their treatment. “Tuguy will strengthen the support network for people with hemophilia and allow the monitoring of treatments by health professionals in real-time. The app is a donation from FBH to all Hemophilia Treatment Centers, that are very enthusiastic about using it”, says Tania. Currently, there are other applications for controlling and monitoring patients with coagulopathies, such as myPKFiT. But Tuguy differs from these other apps because it is free and mainly because it is not specifically aimed at a particular drug, being accessible to all possible types of patients. “The FBH platform was developed to adapt to the different realities of each region where it will be used. The purpose with Tuguy is to facilitate the work of health professionals in HTCs. Our team listened carefully to the needs of health professionals and patients until arriving at an innovative app that would make a difference”, tells the president of FBH. In 2019, the Hemocentro de Pernambuco (HEMOPE) participated in the pilot project by showing the needs of the HTC doctors and helping to build the functionalities that, in practice, patients and health professionals would need on the platform. Before the pilot project took shape, an international survey was carried out to identify the applications for hemophilia that existed in the world, Tuguy was tested and approved.

Dr. Juliana Dias, pediatrician of HEMOPE, says that the technology of FBH will be a “facilitator of lives” and it was “an affectionate way” that FBH found to strengthen the relationship between HTC and patient. “For the patient, Tuguy is a means of communication with the HTC in a faster and more effective way”, says Juliana. The health professionals of the HTCs chosen to participate in the project, received training from FBH to use Tuguy. According to the manager of Hemorrede of the State of Alagoas, the hematologist Verônica de Lima Guedes, the app in HTC will be important for monitoring the treatment of patients. “We hope that from now on we will be able to have a more regular and controlled monitoring of the infusions of clotting factors and the events that these patients may experience and the most important point: if they are really adhering to prophylaxis”, she says. “We have the entire Tuguy platform ready on HTCs in Recife, Porto Velho, Brasília, Florianópolis, Porto Alegre, João Pessoa, Maceió, Aracaju and Curitiba. Now, FBH is structuring the app donation agreement to the HTCs that will use it. It is important to remember that the support of the affiliated state associations has been essential for this dream to come true”, says the president of FBH, Tania. In these states, training has already been carried out for health professionals to use the app and each state has made the necessary adjustments to their realities. In October 2020, Tuguy was presented to the World Federation of

Hemophilia (WFH) at a meeting with over 140 countries. WFH learned about the technology through the regional manager representing South America, Fernanda de Carvalho Geiger. “I told her about Tuguy at a meeting we had and she was delighted! It so happened that some time later the WFH had a meeting on the innovations carried out by some patient federations around the world that could be used remotely and in pandemic times. WFH was identifying experiences around the world with this proposal and Fernanda reported our experience with the app. FBH held the presentation which was a success! We realized, at that moment, that there was no technology like this, free use to patients, in the world. It was very interesting to have people from all over the world, involved with hemophilia treatment, interacting and wanting to know more about our project”, says the president of FBH. Soon, Tuguy will be available for general use. FBH is making a donation term available to each board of HTCs in compliance with the rules of the General Law of Data Protection (LGPD, initials in Portuguese), created to ensure the security and privacy of data for all patients. “In all the HTCs we visit, we have already adapted the app, trained healthcare professionals, organized the databases, technically everything is ready. The contract will make the security of patient data clear and this is very important. We are curious to know how they will join Tuguy, but we are sure that the work together between FBH, HTCs, affiliated state associations and patients will make a great difference in the quality of life for all”, tells Tania, president of FBH.

FEDERAÇÃO BRASILEIRA DE HEMOFILIA

Gioconda Romero

Fundación Panameña
de Hemofilia

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ENSURING A BETTER QUALITY OF LIFE FOR PEOPLE WITH HEMOPHILIA AND OTHER BLEEDING DISORDERS IN PANAMA

Panamanian Foundation of Hemophilia has the mission to be the organization that is committed, promotor, and guarantor of comprehensive care for people with Hemophilia, Von Willebrand and other congenital coagulopathies at the National level. As a Foundation we have had many challenges and difficulties. The greatest challenge we have been facing since the end of 2019 and the beginning of 2020 with the appearance of Covid-19 is the closure of many institutions. During this time, the focus of the Ministry of Health were matters related to COVID-19, leaving behind the other coagulopathies without any attention and many without treatment.

During this difficult period, the Panamanian Hemophilia Foundation developed strategies for medical care, transfer to hospitals, and treatment, keeping the entire community of congenital coagulopathies informed, and transforming the annual plan of activities via virtual modality. We managed to modify our workshops, teaching, our activity programs, telemedicine, transfer of people with difficult access, home delivery of medications for prophylaxis, technology serving as our main ally. Today, with the reopening of many HTCs and face to face meetings we have been able to carry out our activities, although with limited attendance. On Thursday, November 25, 2020 we held our first meeting of "Uninsured People With Coagulation Disorders", with an attendance of 45 people, including members of the World Federation. The first meeting of "Uninsured People with Coagulation Disorders" was held with the purpose of raising awareness and orienting them towards future assistance with the reopening of the Coagulopathies Clinic at Santo Tomas Hospital. The highest percentage of people with various coagulation disorders is found in Panama City. Over 30% of the population that are without social security receive their care at Santo Tomas Hospital. The Panamanian Hemophilia Foundation with the support of the World Federation of Hemophilia, have held meetings at Santo Tomas Hospital regarding the reopening of a Satellite Clinic for the care of various blood disorders, under the direction of Dr. German Espino, head of the Hematology Department.

In this meeting, Mr. Cesar Garrido, President of the Federation, highlighted the work that the World Federation of Hemophilia has been doing with all hemophilia organizations worldwide with training, seminars, preparation workshops for new members with the main objective of providing comprehensive care and treatment for all. The Panamanian Hemophilia Foundation was congratulated for their perseverance in making their mission a reality. Dr. Espino mentioned that having a meeting with his future patients, listening to their experience in health and medical care, has strengthened the decision to reopen the Coagulopathy Clinic. The constant struggle to open a patient care unit was difficult, but it is now a reality. Doctor Espino, he should be mentioned found his source of inspiration for the reopening of the clinic from the hematologist Rafael Aparicio, and the way he has directed the hematology structure in the hospital complex Social Security Fund of Panama. On behalf of the Foundation, the executive director, Lic. Alaisa Arauz, thanked everyone present and congratulated all the volunteers of the Panamanian Hemophilia Foundation for being constant and never giving up, a triumph that benefits everyone, for a better quality of life.

In Panama the following cases have been recorded:

- Hemophilia A - 281
- Hemophilia B - 37
- Von Willebrand - 521
- Other coagulopathies - 104

Minerva Cruz Ramírez
Federation of Hemophilia of the Mexican Republic
Mexico

PROMOTING AND FACILITATING THE WELL-BEING AND QUALITY OF LIFE OF PEOPLE WITH HEMOPHILIA AND OTHER BLEEDING DISORDERS

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The Federation of Hemophilia of the Mexican Republic (FHMR) is a non-profit organization formed by and for people with hemophilia and other inherited coagulation disorders. It seeks to improve access to comprehensive health and encourage greater participation of society, generating public opinion and conscience through various activities. For 30 years, the FHMR has been working with altruism and professionalism with the aim for people living with hemophilia and other coagulopathies in our country to have adequate treatment, regardless of the health institution in which they are cared for. One of the strengths of the FHMR are the State Member Associations; since it allows the increase of our capacities for the development of our activities at a local level. Through the existence of the association, we have designed activities and campaigns aimed at people with hemophilia and other coagulopathies, their relatives, doctors and health professionals; in the same way, we have sought to give visibility to suffering within each of the spheres that make up Mexican society.

FHRM
Federación de Hemofilia de la República Mexicana, A.C.

The main activities carried out in the Federation are:

- Hematological Consultations
- Physical medicine and rehabilitation
- Social work, providing care for people with hemophilia and other coagulopathies.
- Psychological assistance
- Educational days for doctors and community members on health issues to provide better care for patients with coagulopathies
- Political advocacy
- Management of social networks and public communication

The main areas that provide care in the Federation are:

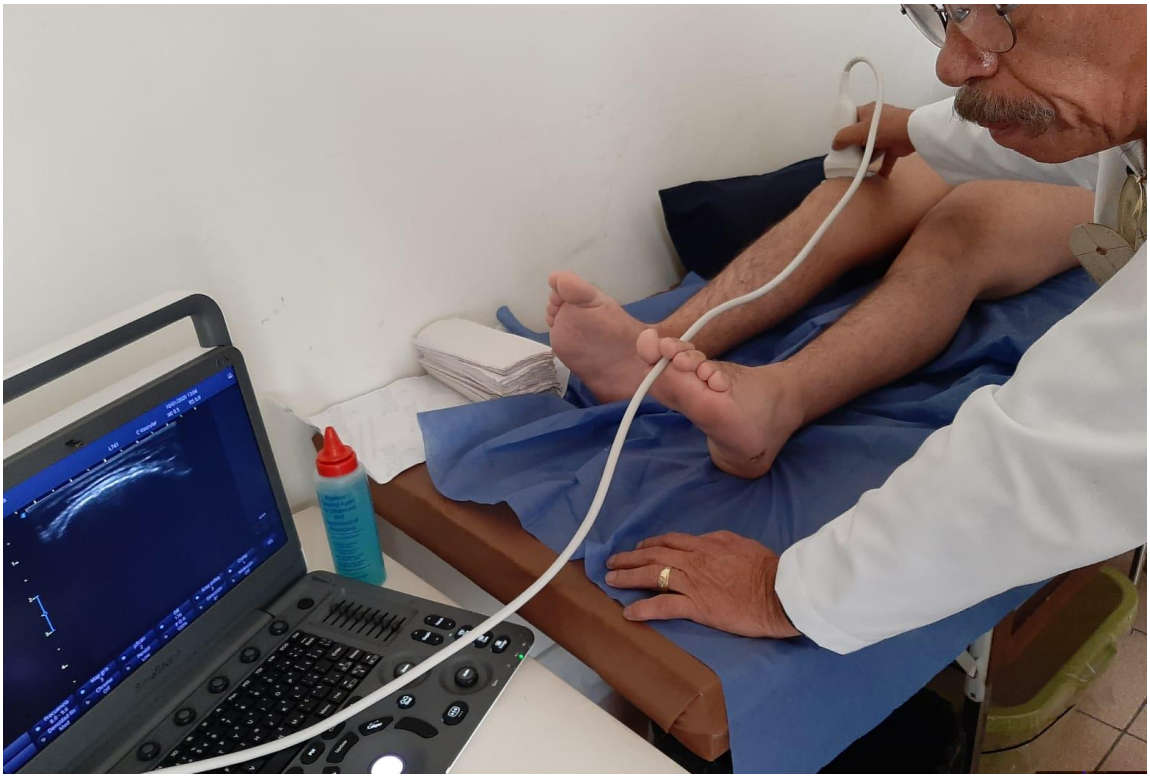
- **Psychology**

The knowledge that on one hand, living with a chronic medical diagnosis produces a great change in the life of the patient and his family, causing anguish, despair, sadness, impotence, among other reactions; on the other hand, the treatment also generates different psychosocial responses interfering, at times, in a therapeutic non-adherence; this leads to the increase of variables that make this population even more vulnerable, impacting on their quality of life. For example, hemophilia, being a hereditary disorder, generates a high emotional burden and stigmatization in many mothers, who sometimes feel singled out by neighbors, friends, even by some of their family; when they experience episodes of pain and bleeding in their children, guilt usually prevails. Likewise, there may be social rejection towards their children due to ignorance and visible symptoms that condition disability in most cases, limiting opportunities for personal and professional development, especially in population with low academic and economic levels.

The importance of the above statement makes the intervention of a specialized psychological treatment very important, as the FHMR understands that it consists of the application of techniques by a professional, in order to help people face their challenges and solve them; it therefore proposes "Hematological Psychology", a project led by Dr. Ezequiel Martínez Martínez, with the objective of promoting and facilitating the well-being and quality of life in all spheres that involve a person as a patients with hematological diseases, their families and health personnel who care for them.

- **Physical Medicine and Rehabilitation**

The FHMR has an area of physical medicine and rehabilitation, where interdisciplinary care is provided for patients with hemophilia, to treat musculoskeletal problems that are present in patients, caused by hemarthrosis and thus enable them to avoid arthropathy and resulting in disabilty. Treatment should always be individualized and tailored to the patient's needs. The rehabilitating physician is responsible for evaluating the patient and making a diagnosis, the physiotherapist performs the treatment with therapeutic exercises accompanied by physical agents and manual therapy; in this way our goal is to relieve pain, sensory disorders, decrease the frequencies of hemarthrosis, recover proprioception, reduce deformities and disabilities, and improve patient functionality and above all the quality of life. Our purpose is prevention, maintenance and recovery. We have a hybrid treatment (face-to-face / virtual) to provide care to all patients who are in the Mexican Republic.



- **The Mexican Registry of Coagulopathies**

The Mexican Registry of Coagulopathies (MRC) is a census conducted by the FHMR to know how many patients there are and what the main needs of people with coagulopathies in the country are. The area of the Mexican Registry of Coagulopathies is responsible for keeping the census updated with reliable and accurate information of people with hemophilia. The patient is contacted personally or remotely so that, with the support of the FHMR multidisciplinary team, the immediate needs of members of our community are identified. We provide community members with advice on the correct use of the MRC platform and mobile application. This is very useful because people with coagulopathies can keep track of their bleeding and infusions, which is very important to guarantee the ideal treatment for each of them.

The main achievements of the Federation are:

- 2019 National Health Award
- Inclusion of hemophilia in popular insurance in 2011.
- Start of prophylaxis in some institutions
- Home delivery by IMSS in different states.
- Inclusion in Seguro Popular of treatment for patients with inhibitors and von Willebrand's disease.
- Creation of alliances with the main health institutions and civil organizations.

Sabina Frisina
Associazione Emofilici di Reggio Calabria
Italy

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SHARING EXPERIENCE REGARDING HEMOPHILIA: THE ACTIVITIES OF A LOCAL HEMOPHILIC ASSOCIATION

Born from the need to establish sharing relationships between families with haemophilic children and with haemophilic adults, the Haemophilia Association of Reggio Calabria has always moved around the area trying to use all the possible resources it provides. Meetings were organized between families to share their experiences and their own experience with the disease. Meetings between families and expert mediators and psychologists to understand better how to explain the existence of the disease to their children and face the difficulties of everyday life. The children related to each other, sharing the experience of growing up, of facing a reality that is not always the same as that of others. The various convivial moments, including with adults, have made it possible to establish a strong link between the past, present and future of haemophilia in everyone's life, in the innovation of treatments, in the new possibilities of approach. Not infrequently, in facing the diagnosis of a rare pathology for oneself or for one's children, the first feeling is that of loss and loneliness, as if what has happened to us is an event that cannot be shared with anyone else, which cannot be understood and above all unique because rarity makes you feel just like that, rare, unique in the most negative sense. The possibility of

sharing despite a thousand differences, listening to each other, seeing those around us overcome obstacles, being able to speak freely with the certainty of being understood, without having to explain, justify and have to make the best of inquiring and uncertain looks, is one of the added values of the our Association and of associations in general, which came to life from being together. Precisely because of being together, in recent years, the Association has carried out various activities

in the area. Swimming instructors were trained and young and adult hemophilic patients were given the opportunity to attend swimming lessons in the pool together with all the other users, thus promoting integration as well as healthy movement. A similar activity was also started in the gym, always starting from staff training and developing guided courses for the different needs of children and adults with hemophilia. Due to the fact that the consequent pathologies associated with hemophilia affect the joints, physiotherapy screening programs have been launched which have made it possible to monitor the growth of children and the real conditions of adults, preparing the necessary interventions in collaboration and synergy between doctors and patients.

The relationship with the closest and even distant associations has given rise to congress moments where there has always been a space dedicated to patients. Therefore, within the same event, clinicians can exchange their considerations, studies, experiences, while patients can express doubts, perplexities to doctors and learn the state of the art in research and in the situation of new treatments. On behalf of the association, transversal issues are also addressed such as the history and narration of yesterday and today regarding hemophilia with the aim of keeping the attention on this disease and complications always alive, but also to promote correct knowledge to everyone and not just to professionals. In conclusion, the Reggio Calabria Hemophilia Association has always tried to reconcile the two key aspects of associations: sharing the problem to dispel the perception of loneliness and helplessness and the promotion of activities that improve the patient's quality of life and of his family and create a relationship of full trust with doctors, trying to pursue the goal of personalizing care.

Mariana Battazza Freire

Brazilian Association of People with Hemophilia Brazil

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HEMOPHILIA IN BRASIL AND THE WORK OF ABRAPHEM

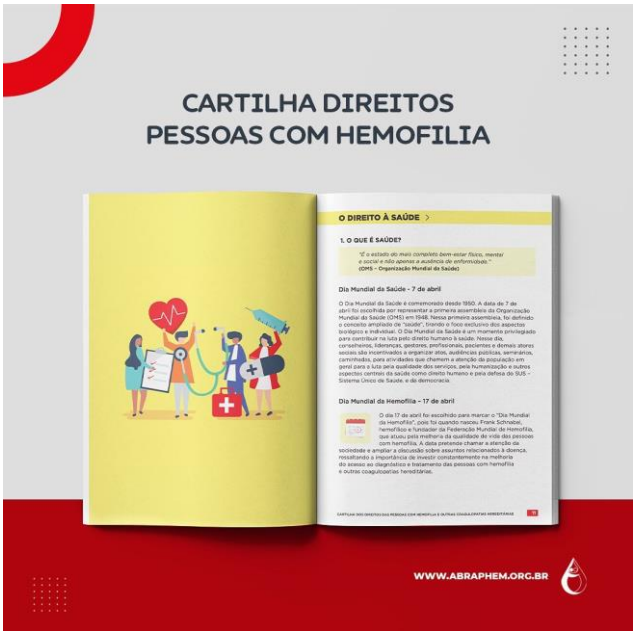
Brazil is the 5th largest country in the world and the 6th in population, with more than 214 million inhabitants. It is one of the most multicultural and ethnically diverse nations on the planet, due to the immigration of citizens from various parts of the world. Public Policy and the quality of health services in Brazil are very diverse and complex and the scenario has currently about 28,000 people with bleeding disorders and 105 Hemophilia Treatment Centers spread across its 27 states and the Federal Districts. The mission of ABRAPHEM, the Brazilian Association of People with Hemophilia, is advocate for people with hemophilia and other bleeding disorders and protecting their interests, influencing the construction and implementation of public health policies and disseminating information to promote the improvement of their health and quality of life. Our Association offers support and guidance to people with hemophilia and their families through campaigns and forums, as well as educational materials. We work by building a network of institutions with the same advocacy objectives to work in partnership and enable the articulation and achievement of these goals. The treatment of hemophilia in Brazil is carried out by the Government Health System (SUS) for all patients, without exception. The current treatment protocol is the same throughout the country and prophylaxis (low dose) is offered for all patients with severe hemophilia (<1%), at any age. Immunotolerance treatment (ITI) for patients with inhibitor is available in the most part of the treatment centers and the current number of patient in ITI is 127. The multidisciplinary teams are held in the Hemocenters of the state capitals and in a few regional Hemophilia Treatment Centers (HCTs), which are located in the interior of the states. The delivery of clotting factor can be done at regional HTCs or other delivery points, but annual exams, physical therapy, orthopedic and dental treatments are almost exclusively limited to the Hemocentros in the capitals. Because few HTCs have complete multidisciplinary teams. Considering that some states in Brazil have the same territorial extension as countries like France, Spain or Germany, the biggest problem to access the treatment is the distance. A patient can live at a distance that varies from 100 to 800 km from the blood center, which makes adequate treatment unfeasible for many of them. In addition, most of these patients have few financial resources for travelling, in uncomfortable public transport inappropriate for their condition. The further the patient lives from the state capital, the less access to multidisciplinary treatment he has.

Another issue that brings inequality to access to treatment in the whole country is the training of health professionals, which is greater and better for professionals who work in large centers than for others. All these facts result in the development of different levels of hemophilic arthropathy in many patients, despite receiving prophylaxis treatment. To address this problem, in addition to advocacy and patient education actions, ABRAPHEM is starting an online training course for dentists in coagulopathies, with the aim of training professionals in the interior of the states and giving better access for patients to professionals able to handle them properly. Coordinated by Prof. Dr. Vinicius Rabelo, technical advisor at ABRAPHEM, this course will take place with monthly mentoring from the teacher to all students, during 6 months.

In the last year, ABRAPHEM created, produced and distributed 3 unpublished educational materials. The first of these is a board game called Dominating the Universe of Hemophilia. The game uses imagination and fantasy to explore a universe with rockets, planets, constellations and, with this methodology, help to re-signify the child's experience with hemophilia treatment, stimulating their autonomy and acceptance of such treatment. The game aims to increase the knowledge of the child and their families about hemophilia and the treatment of prophylaxis and addresses this issue allowing the child to participate in this process as an active person who builds knowledge. The game was distributed by ABRAPHEM free of charge to all children with hemophilia in Brazil, aged between 6 and 9 years, in partnership with 37 Blood Centers and 5 Associations in 23 states in the country in 2021. In addition to the game, 10,000 ID Cards and 5,000 Booklets about the Rights of People with Hemophilia in Brazil were created and distributed. The Card was made to facilitate the patient's journey to hospitals and other health units and contains patient data, blood center contacts, emergency contacts and basic information for health professionals in emergency situations. The booklet guides patients and their families about current legislation and the care rights of patients with hemophilia and provides instructions didactically on how to obtain these benefits.

As part of the actions in reference to World Hemophilia Day, every year ABRAPHEM carries out the illuminating of historical monuments across the country and an educational event to offer the community of hemorrhagic disorders in-depth information in an accessible and didactic way about the different topics that involve treatment. In 2021, the forum took place virtually and had the participation of 265 people live, in addition to about 512 interactions in the chat.

Also on World Hemophilia Day, since 2019, ABRAPHEM has produced and broadcast an unprecedented animated video, with lyrics that addresses different treatment topics (such as prophylaxis, inhibitors, severe bleeding) to teach children about their condition in a playful and motivational way, in order for them to learn more about how to live healthily with their condition. The 2021 video reached more than 22,500 people in one month on ABRAPHEM platforms, proving to be an effective means of publicizing hemophilia among children and adolescents.



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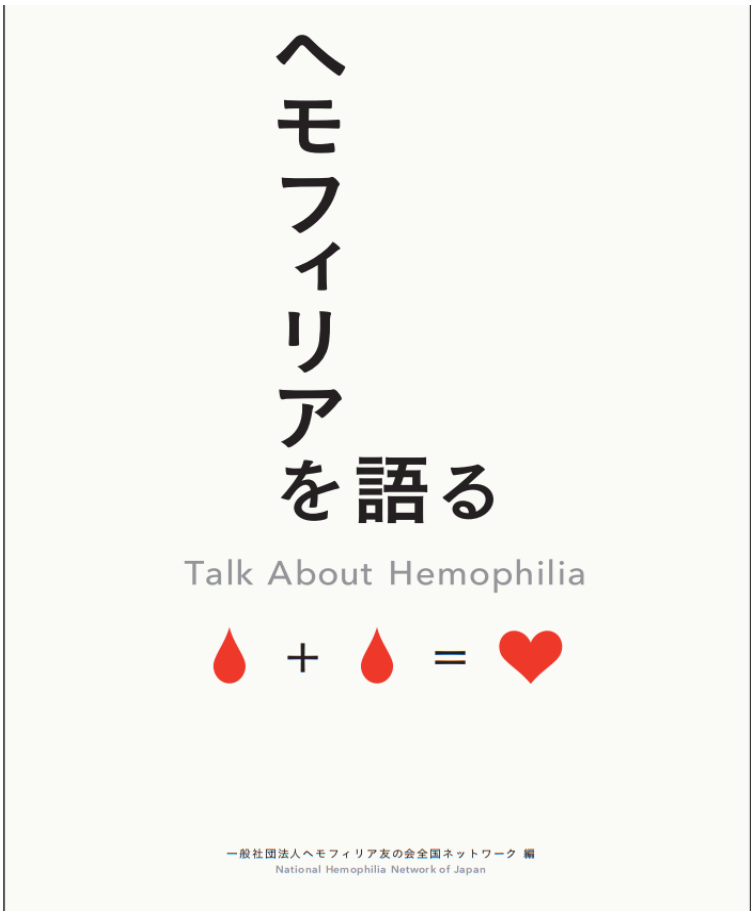
TAKING ADVANTAGE OF A PROBLEMATIC SITUATION: ACTIVITIES DURING THE PANDEMIC

The National Hemophilia Network of Japan（NHNJ）is a liaison body that loosely connects 25 local chapters. It was established in 2008, became an incorporated association in 2012, and was certified by the World Federation of Hemophilia as a Japanese National Member Organization (NMO) in 2016. In Japan, like other countries, we have been badly hit by COVID-19 over the past two years or so. Since 2010, we have held a two-day national forum in a major city approximately every other year, bringing person with hemophilia (PWH) and their families together from all over the country. Since 2018, we have also held one-day mini-forums. However, during the pandemic we had to cancel many of the face-to-face events. For example, the chapter in Tokyo I belong to, Musashino Hemophilia Patient Association which has many children, was also no longer able to hold its annual summer camp and Christmas party. This was a very big blow to us. But we are also taking advantage of this situation to conduct new activities: in 2020, we held a virtual symposium on gene therapy and women with congenital bleeding disorders, and in 2021, we held a virtual symposium on hemophilia care and medical policy, both

with archived videos available. In 2021, we published "Talk About Hemophilia" which consists of eight articles of virtual group discussions among PWH, medical professionals, and other stakeholders across Japan. This booklet has been very well received, since it provides a rich and intense link between the past, present, and future of hemophilia in Japan.



The popularity empowered us to produce a pdf English translation of this book. Once available, we hope to share this achievement with the rest of the world.

The situation of PWH in Japan is relatively satisfactory compared to other countries. The product is available and PWH can use it without copay. However, there are regional and facility disparities within a small country, and there are certainly PWH who are not receiving adequate treatment. Despite the difficult situation of the corona disaster, we are continuing our activities as far as possible. Recently, after overcoming long-standing political restrictions, we have finally been able to donate blood products overseas from Japan. Steady progress is also being made toward the establishment of a national patient registry, which has been a long-standing concern. In cooperation with advocates around the world, we would like to pursue a bright future for hemophilia.

Charles Kibe Njogu

Kenya Hemophilia Association

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EXPANDING AND BRINGING ACCESS TO CARE FOR PATIENTS WITH HEMOPHILIA

The Kenya Hemophilia Association (KHA) was established in Nairobi in 1979. In 1992, it was recognized as a National Member Organization (NMO) by the World Federation of Hemophilia (WFH). With this status, it is the official Kenyan patient organization in charge of representing the rights of all patients living with Hemophilia and allied bleeding disorders in Kenya. Kenya Hemophilia Association's primary role is access to care for all patients with hemophilia. We currently have 10 clinics across the country and all our clinics are located in a county hospital/referral. Kenya Hemophilia Association is in partnership with World Federation of Hemophilia, ROCHE Kenya Ltd, Novonordisk Hemophilia Foundation and The Ministry of Health (Kenya). We have been able to keep expanding and bringing access closer to the patients. In the next two years we aim to open a minimum of 12 more facilities as well as to train more nurses, doctors, laboratory technologists and surgeons on hemophilia care and treatment.

Kenya Haemophilia Association