

**Mariana Battazza
Freire**

Brazilian Association of
People with Hemophilia
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Editor: G. Sottilotta
Director: D. Greco Malara

e-mail: ojhm@hemonline.it
<https://www.hemonline.it>



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 HTC 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.

