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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.



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