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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 HTC's 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

