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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.



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 disability. 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.

