



Management and Transfer of knowledge in the National Member Organizations

Biennial Work Proposal

INTRODUCTION:

America in recent decades has made great progress when it comes to people with hemophilia as well as other bleeding/coagulation disorders; This is largely due to the work of the World Federation of Hemophilia (WFH) and the commitment of the National Member Organizations (NMO) to carry out various Strategic Plans, with 2021-2025 being the one that reflects the premise “Treatment For All”.

Reaching this point was thanks to the commitment of the ONM to improve patient records, and the coordination with Medical Care Providers (PAM) for access to treatments as well as new therapies, which have not only improved the quality of life of people with coagulation disorders and their families, but has also demonstrated the preponderant value that ONMs have in each country; This has led the WFH to prioritize “Establish standards of excellence for ONM and support its adoption” as a priority for this five-year strategic plan.¹

This position that they have taken, as builders of social ties, consolidating action strategies on a continental basis has allowed, for example: the empowerment of patients and their families, the increase of patient registries in each country and greater access to various therapies.² All of this has been achieved thanks to the commitment to redesign the educational and training offerings of both the WFH and the Coalition of the Americas (COA), in order to maximize the impact on the NMOs.

It is evident that the achievements achieved in this last decade are thanks to the work and concentration of efforts of the ONM in the optimization of resources. The human capital they have is not only diverse, but has been trained to strengthen their work in order to improve access to care and treatment in their country. From this FMH – COA – ONM joint, the main goal can be achieved: greater access to diagnosis, treatment and care for people living with coagulation disorders.

It is important to mention that Latin America and the Caribbean is today, according to WFH data, the continent that has the most growth in sustained patient registration and therefore the one that will require the most opportunities for access and treatment. If we look at Europe, for

¹ Strategic Plan of the World Federation of Hemophilia. Available in <https://wfh.org/wp-content/uploads/2022/04/WFH-Strategic-Plan-2021-2025-EN.pdf>

² Annual Global Survey of the World Federation of Hemophilia.. Available in <https://wfh.org/es/investigacion-y-recoleccion-de-datos/sondeo-mundial-anual/>

example, it currently has a “ceiling” in relation to the registration of new unidentified patients since it has high percentages per country and in its entirety of registration, the same happens with the USA and Canada. These examples also have resources to guarantee cutting-edge treatments and new therapies, thus ensuring that future generations already have incorporated some necessary concepts to continue down that path. On our continent this must be built, that is, the new generations must be given the knowledge of the ONM and its current leaders, but we must also sow the need to open up their treatment ideas so that they can think about different options, otherwise they will not be able to do so. continue with the same management model and thus losing the opportunity to innovate with other alternatives.

For these actions to last over time and their achievements to continue bearing fruit, it is necessary for NMOs to develop new competencies, and for this internal feedback is necessary: promoting, valuing and managing knowledge among all members of the Organization.

Clearly, the 21st century presents us with great challenges: advances in therapies, new purchasing mechanisms and the tendency to value the patient again in the treatment decision-making process and, above all, new directions and challenges for ONMs where they must. examine their lobbying models and advance a process of professionalization of their members as well as modernization/innovation of their processes.

The COA together with the WFH sees it as unavoidable that to achieve the 2021-2025 strategic priorities, during the coming years, it is necessary to provide theoretical and practical tools to begin the management and knowledge transfer process within the ONM. To achieve these objectives, the participation and commitment of each and every member of the ONM is vital, as well as encouraging the incorporation of young people to begin the transfer of the most precious intangible asset, which is knowledge; Thus, the NMOs begin a process of consolidation and sustainability of knowledge management.

STATE OF SITUATION

The NMOs that make up the COA are national hemophilia organizations that represent the interests of people with hemophilia and other inherited bleeding disorders in their respective countries.³

The constitution of these has been given by doctors, family members and/or patients with some type of bleeding/coagulation disorders; All of them have been recognized by the WFH as ONM and since then their leaders, managers and members have been dedicated to maintaining it.

Today the COA sees it necessary to begin focusing ONMs towards value creation and sustained suitability, two essential elements in the current environment, characterized by changes and the imperative need to adapt to new realities.

For this, the Knowledge Management that the members with the most experience must carry out for the new generations that join is essential not only to define the vision, processes and structures but also to guide the new strategies with the PAMs.

ACTION PLAN

The work plan with the ONMs will be a roadmap that has goals and objectives, respecting the identity of each Organization because we understand that each Country has its idiosyncrasies,

³ <https://wfh.org/es/encuentre-apoyo-local/>

and there will be as many paths as there are ONMs to achieve the goals, meet the objectives and achieve results. within the next 12 months within the framework of the proposed work plan.

It must be understood that change management consists of accompanying people in organizations during the transition from the current situation to the desired situation; Under this framework the following will be addressed:

- Tools to facilitate the successful implementation of strategies of transformation processes.
- Identification and addressing antagonistic factors: personal resistance – organizational barriers.
- Characterization and management of commitment factors.
- Perception of Strengths, Opportunities, Weaknesses and Threats by ONMs
- Design of a strategic action plan for the ONM
- New ways to track and monitor the processes of change and consolidation of new habits effectively.