



## Scholarship support project for leaders of the continent with Fedhemo.

### “Education and experiences are part of the treatment”

It is known that the NMOs of our continent have a disparity in their levels of development, both from the medical and social dimensions. These differences are due to various causal factors such as aspects of the politics, economy and structural matrix of each State, and also to organizational and planning aspects of each ONM.

It is vital to be able to provide a minimum support of tools for the advancement of said ONMs that still have to develop various internal areas and, in turn, must have a better intervention in the public health policies of each country. This with the clear objective of improving the treatment of patients with hemophilia, access to medication and creating multidisciplinary treatment centers.

The challenge then is to be able to provide the tools, knowledge and transfer of experience and learning to the leaders of each NOM, with the aim of motivating and training them as professional leaders in the matter. We currently have a significant number of local, national, and regional leaders who are recognized by their peers, the patient community, and physicians, but still need to undergo a theoretical and experiential training process and be able to be in contact with various world leaders and continental organizations from various organizations that have already followed this path, in order to learn from each story.

It is then that leaders not only need educational training but also to participate in international educational events for two purposes: - to gain experiential training in situ and - to see in action and hold meetings with leaders from various organizations that have been successful. In this way, we believe that we will be able to start a process of educational and experiential training for leaders who require such training to improve treatment in each country.

This is a cooperation project between the COA, WFH and the Spanish Federation of Hemophilia, a national benchmark in Spain as an entity that supports and represents people with hemophilia and other coagulopathies, located in Madrid, venue of the next World Congress of the WFH in 2024.

The Spanish Federation of Hemophilia (Fedhemo) was established in 1971 by a group of people with hemophilia and other coagulopathies with disabilities and their families who came together with the aim of carrying out actions that contributed to improving the quality of life of people with coagulopathies, this being the main mission of the entity. This mission materializes in carrying out actions aimed, among other objectives, at improving medical

treatment, its access, and comprehensive care for people with coagulopathies, taking into account the person from a bio-psycho-social perspective. Fedhemo brings together two delegations (Extremadura and Castilla La Mancha) and twenty member associations (Álava, Andalucía, Aragón-La Rioja, Asturias, Balearic Islands, Burgos, Cantabria, Galicia, Guipúzcoa, Las Palmas, León, Community of Madrid, Málaga, Murcia , Navarra, Salamanca, Tenerife, Valencia, Valladolid, Palencia and Vizcaya) representing 3657 people with hemophilia or another coagulopathy in Spain.

In addition, Fedhemo belongs to and actively collaborates with other national and international entities in the field of disability, rare or infrequent diseases and congenital coagulopathies: Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE), the Platform of Patient Organizations (POP), Spanish Federation for Rare Diseases (FEDER), Eurordis, World Federation of Hemophilia (WFH) and European Hemophilia Consortium (EHC).

Since Fedhemo's vision is to defend the rights of people with hemophilia and other coagulopathies and their families through an active and participatory role with the Public Administration and, especially, with the National Health System, it is positioned as a national benchmark for hemophilia, contributing and transferring the needs of patients for support in the preparation of socio-sanitary plans.

For Fedhemo it is important to participate in mentoring where it can collaborate to strengthen the work of entities that work with people with hemophilia from other countries. It is an organization with experience that will play an important role in the formation of future leaders of young people with hemophilia, also enriching itself with the knowledge and practices of other countries.

#### **Goals:**

- That the leaders of the region obtain the necessary tools at a practical level to carry out these debates and influence public health policies in each country.
- Complement the virtual theoretical approach of the Workshops and Activities that both the WFH and the COA dictate, but in a practical experiential dimension in situ.
- Generate the analysis of possible successful practical experiences in various organizations and study the application in each country of residence of the leaders.
- Encourage scholarship holders to rethink current formats and visions of the rights to health in each country in comparison with EU standards.
- Make direct contact with different Spanish public authorities dedicated to hemophilia treatment and access to enrich their national strategies.
- Learn about the treatments and methods of coverage and access in Spain to replicate them in their countries.
- Know the working modality of Fedhemo and generate critical thinking in the structure of each ONM.

**Agenda of tentative contents:**

The following is a list of topics/activities that would be part of the agenda for the scholarship recipients' visit to Fedhemo (to be confirmed):

- Visit to the Fedhemo organization, learn about its structure, authorities, way of working, etc.
- Participate in the National Board of Directors of Fedhemo, as an overseer.
- Visit and work meeting with a laboratory with a factory in Madrid to find out details of the preparation of the factors, their processes and biosafety aspects.
- Meeting with public authorities from the Ministry of Health and international financing agencies from Spain and the EU.
- Meeting and visit to COCEMFE, ONCE and CERMI in order to receive training on the rights of third generation people with disabilities.
- Theoretical/practical training with specialized teachers on: Health Technologies, drug-economic analysis, public tenders, biosafety, etc.
- Visit to the multidisciplinary hemophilia care center at Hospital La Paz in Madrid.
- Active participation in the 2023 National Youth Meeting of Fedhemo.
- Visit and meetings with the Royal Victoria Eugenia Foundation.

**Number of leaders to be awarded:**

Our intention is to be able to make a selection of 5 leaders, with the following profile:

- 1 adult coordinator of the program
- 5 young people under 35 years of age
- Men and women equally
- Real and verifiable commitment in your NOM
- Patient or immediate family
- Written commitment to continue with their tasks at the ONM for at least 6 months after their participation in the mentoring
- Letter of reference from the President of the ONM endorsing the application
- Proactive and interested in obtaining new knowledge.

**Report and subsequent tasks:**

Each leader who participates in the mentoring at Fedhemo must then:

- Choose a topic from those discussed in your mentoring

- Together with the organizational Coordinator of the Project (as tutor) guide a planned Work Plan to obtain a new achievement of said subject.
- Put it to the consideration and contributions of the CoA and Fedhemo for its execution.
- Carry out the scheduled actions with the objective of achieving the planned goal.
- Prepare a report in the middle and at the end of the Plan on its state of progress and achievements.

**Mentoring view details:**

- Arrival in Madrid: November 19
- Return from Madrid: November 26
- Staying in a nearby hotel