



AMERICAN REGISTRY OF WOMEN WITH
CONGENITAL HEMORRHAGIC CONDITIONS

Context

The situation of the community of women with coagulation disorders has certain characteristics that influence their possibilities for treatment, as well as for carrying out projects and ways of life. The non-consideration of their symptoms, late or absent diagnoses, lack of comprehensive treatments are some of the aspects that must call us to build a new perspective, with possibilities and opportunities for all of them.

New categorizations and considerations at the international level invite us to look again at this group, also in the context of America.

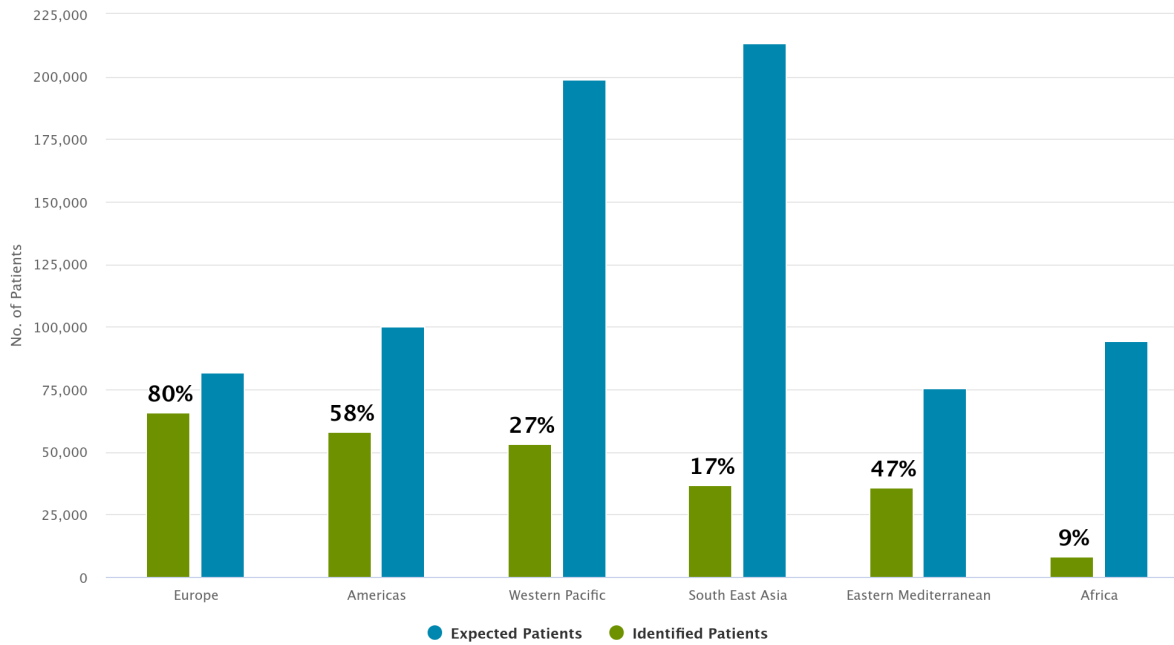
The Coalition of the Americas, with its Committee of Women with Bleeding Disorders, proposes work that visualizes the reality of women who go through this situation in America in order to develop and propose strategies that improve both their diagnosis and access to treatments. integral. The lack of precise data regarding the number of affected women, where they are located, what access to diagnoses and treatments is like, should be the first task to be proposed.

Thus, the next actions will have as their primary objective the construction of an AMERICAN REGISTRY OF WOMEN WITH CONGENITAL HEMORRHAGIC CONDITIONS (Hemophilia A and B- Von Willebrand – Deficiency of rare factors: VII, X, XI, XII, fibrinogen – Thromboplasties: Sd Bernard Soulier, Glanzman's Thromboasthenia)

This information will contribute significantly to generating actions that improve your current situation. It will make it possible to generate better care policies, provide care centers where necessary, strengthen other centers, carry out lobbying tasks with governments and fight for better care for all.

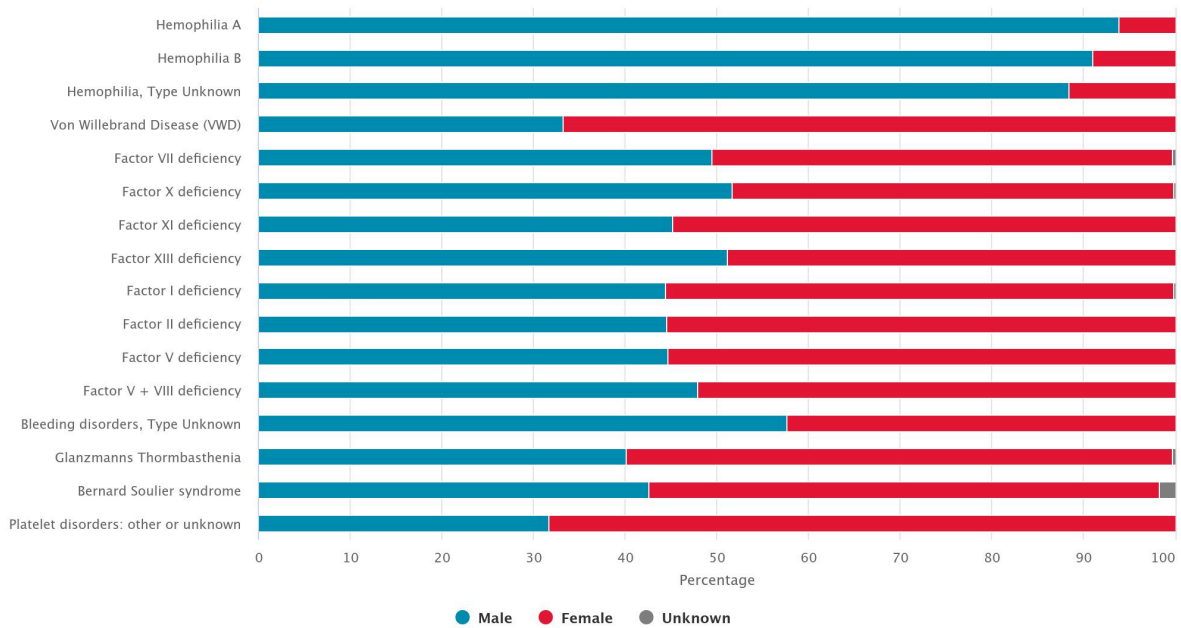
We know about the diversity of America, diversity of resources, possibilities, diagnosis, experience in the different patient organizations as well as the number of projects that each of these organizations is carrying out. There is also variety in the type of relationship with health professionals and the patient organization, which will also generate particular aspects to consider when implementing this registry. For this reason, considering the reality of each country, various registration possibilities will be proposed, so that each organization can adapt it to its reality and possibilities.

Expected versus identified patients by region 2022



Data source: WFH Annual Global Survey

Bleeding disorders by sex - Americas 2022



Data source: WFH Annual Global Survey

PROBLEM

The absence of precise data on the number, location, access to diagnoses and treatments of women affected with a congenital hemorrhagic condition in America makes it significantly difficult to develop appropriate actions that contribute to improving their situation. It is necessary to be able to generate the necessary tools for each National Member Organization to prepare its Women's Registry based on information on male patients with hemophilia and other resources.

Without records, access to treatment is unfeasible, therefore the most important problem is to be able to generate it at the national level, with the clear objective of improving treatments and access through health coverage.

OBJECTIVES:

- Include in the national registries of the COA ONM the current categorizations for women with a congenital hemorrhagic condition.
- Increase registries of women with a congenital hemorrhagic condition in all national registries of COA member countries.
- Generate regional data on women with congenital hemorrhagic condition.

IMPACT

Include the current categorization of women with congenital hemorrhagic conditions in all national registries of the ONM participating in the COA.

Increase by 40% the records of women with congenital hemorrhagic conditions in the national registries of 4 countries in America.

Build an American registry of women with congenital hemorrhagic conditions with participation from all 24 COA countries.

ACTIVITIES

Stage 1: Plan of activities

- *Establishment of local women references in each of the countries belonging to the Coalition of the Americas.*
- *It will be requested that each person responsible for the organization be able to convene their female representatives to form this working group.*
- *If there is no group made up of women in the ONM, someone who has the approval and recommendation of the authority may be proposed.*
- *General description of the current situation of Women with coagulation disorders in America, considering treatment, diagnosis and registration.*
- *This report will be prepared from data collected after a brief survey sent to each of the ONMs.*
- *Communication and dissemination actions for this report.*
- *With the information received, a categorization of patient organizations in America in relation to women will be established. The criteria may be: There is no record. There is registration. Who owns this record (Professional, care center, private, state) This categorization will allow different trainings to be carried out, support with different types of support according to the need.*
- *From each group formed, one/two countries will be selected where the activities will be carried out in the first year of this project, so that in the next year it will be replicated in another country of that same group. Selection criteria: type and experience of the ONM, relationship with health professionals, number of people who assume responsibility for the task.*

Etapa 2: Execution

For the entire region:

- *Development of awareness and recognition strategies for this group in America: Advertising campaign for networks to recognize symptoms and places of care.*
- *Flyer design, posters, plaques explaining the importance of registration as a way to complete the form. Journalistic notes.*
- *Training instances for health professionals in light of the third WFH treatment guidelines*
- *Virtual training by international specialists. Topics: Comprehensive diagnosis and treatment for women with bleeding disorders in care centers.*
- *Training instances for members of the ONM*
- *The theme will obviously revolve around women but focused on registration, how to obtain data, how to register.*

For selected country

- *Visit to the selected country. Meeting with members of the ONM, with health professionals.*
- *Communication of the action proposal.*
- *Development of a registration instrument for women with congenital hemorrhagic conditions in America according to the characteristics described.*
- *Registration campaign steps to be developed (includes communication) Preparation of strategic actions for dissemination and data collection.*
- *Training for managers*
- *Establishment of times for each planned action and frequency of reporting data.*
- *Launch action in each country and region.*
- *Monitoring and support actions*

For COA women's committee

- *Preliminary information collection*
- *Report making*
- *Propose training actions for professionals and ONM on registration*
- *Shared meeting with countries of the same category in order to explain and refine dissemination steps, times, collection and those responsible for the data*
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- *Project monitoring plan: communication to representatives of monitoring agreements, deadlines and those responsible. Periodic meetings between representatives. Report analysis.*
- *Establish criteria, instrument, times and those responsible for the storage of general data:*
- *Data collection every two months (General spreadsheet)*
- *Assignment of a Women COA member to each country to carry out exchange and registry monitoring tasks. (Continuous)*
- *Analysis of collected data.*
- *Final report.*