



Network for Life

EN RED PARA LA VIDA
Red educativa entorno a la Hemofilia
y otros trastornos de la coagulación en el
departamento de Antioquia.

Introduction:

This is an experience that was born in the League of Hemophiliacs of Antioquia in order to generate a network of support for people living with Hemophilia and Von Willebrand disease from the department of Antioquia; mainly from municipalities that are outside the metropolitan area, providing opportunities for integration and projection among different actors such as Hospitals, Municipalities, Secretaries of Health, municipal courts, patients and families. The goal is to reduce the risk of bad treatment and hence the effects of the disease and negative impacts on the quality of the patient's life

Objectives:

- To establish a support network around the people living in Hemophilia and other bleeding disorders in the department of Antioquia.
- To identify the different actors involved in hemophilia and other bleeding disorders in all municipalities of Antioquia.
- To build linkages that integrate the different actors in the public and private sectors related to hemophilia and other bleeding disorders in all municipalities of Antioquia.
- To promote actions and develop clinical and social support through specific work plans for people living in Hemophilia and other bleeding disorders.
- To train all persons connected with the network, in order to improve the quality of care and the health status of patients and their families.
- To maintain cultural and scientific relationships and exchanges with public and private entities involved in the network to strengthen the development and continuity of this in time.

Materials and Methods:

- Formats to finalize the agreement and participation in the network.
- Characterization Survey educational booklet for the family.
- Evaluation and professional Physiotherapy, Psychology, Nutrition, legal advice
- Physical infrastructure to gather all patients and families through the strategy of sunny days
- Awareness meetings with local authorities.
- Home visit and application of characterization survey for people living in Hemophilia, von Willebrand and related factors.
- Training territorial and professionals in health, belonging to the IPS, Hospitals and municipal entities.
- Assessment of people living in Hemophilia, Von Willebrand and related factors.
- Roadmaps for the people living in Hemophilia, Von Willebrand and other related factors.

Results

Counsel:

Of the population of people living with Hemophilia in different regions of Antioquia 97% were attended to. About 80% of the population who participated in the project manifested a legal requirement. Of this percentage 40% relates to the aforementioned problems such as comprehensive access to treatment and recovery of economic assessments and aid transportation. 2 % were totally abandoned by the public institutions responsible for managing the disease.

Legal intervention carried out by the project helped 31 families with affirmative action that removed obstacles of inferiority and guaranteed full enjoyment of their constitutional rights to health and human dignity.

Psychological Area:

67 Psychological assessments were carried out, in which participants mostly agreed to the consultation space and were receptive to recommendations. The proposed individual counseling was carried out taking into account the setting of goals, the use of dialogue methodology to achieve the verbalization of the participants and the detection of the main difficulties. Each of the participants were given different treatment recommendations based on their problems and needs

Physiotherapy Area:

117 physiotherapeutic physical assessments were made corresponding to 48.7% of the total beneficiary population in different regions. The goal of these assessments was to determine the musculoskeletal status, functional ability and other aspects to generate recommendations to improve overall fitness according to the individual situation. They determined specific strategies to facilitate the implementation of the recommendations and physiotherapy treatment and communicate with each patient to determine the evolution of the process and improve their overall fitness

Nutrition Area:

64 nutrition consultations were carried out as part of the project. It should be noted that only 20% of the people were tested. From the nutritional consultation the poor accessibility of food was evident, especially due to lack of economic resources, which prevented adequate intake. In some people induced anorexia was evident due to the stress of the disease and malnutrition.



Conclusions:

- The involvement of local authorities provided great support for the training of the network, since they encouraged management processes and community participation in different municipalities.
- The people living with Hemophilia were mostly found in low income situations, some with better access to health services or improved housing, school and jobs. Particular cases are being forwarded to the Committee on Clinical and Social Support of LIHEA, to be analyzed one by one and generate support strategies that take into account the existing contact in the municipalities and rural areas and the potential to contribute to their quality of life.
- In each municipality, and after each experience, the Network for Life confirms its importance by encouraging people to become sensitive and aware, and to contribute to improving the welfare and quality of life of people with hemophilia. In this way, a Social Security Healthcare System lacking supportive public policies can encourage the creation of new policies, and create interest in pursuing the subject to improve comprehensive health treatment and link all the people who are affected by this condition.
- New public policy could not only positively impact the resource management of the overall system, but also allow these families better access to health services and ensure their interests are taken into account in making decisions regarding their process of health, illness and care, including the social transformation of welfare programs.

Author:
David Andres Cuartas Bolivar
Director Programs and projects
Liga Antioqueña de Hemofílicos
Antioquia - Colombia



**LIGA ANTIOQUEÑA
DE HEMOFÍLICOS**
L · I · H · E · A

