

ENSERio LATAM

A study of the Social Healthcare needs of people with Rare Diseases and their families.

ALIBER



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ALIBER en Latinoamérica

- The *Latin American Alliance for Rare Diseases* (ALIBER), is a nonprofit organization which coordinates actions to strengthen the associative movement, give visibility to the FER and represent people with rare diseases in Latin America before local, regional bodies, national and international, creating a permanent joint space to share knowledge, experiences and best practices in social, health, educational and collaborative work areas.
- ALIBER was founded in Totana within the framework of the VI National Congress of Rare Diseases and the I Ibero-American Meeting on Rare and Orphan Diseases in 2013 by 11 patient organisations. **Today, over 500 organizations comprise ALIBER's 59 partners, 54 of which are bodies from Latin American countries. They operate in 16 countries in Ibero-America. Through these, ALIBER represents a group of 47 million people affected by Rare Diseases.**



The Reality of Rare Diseases

- 🌍 There are more than **8,000 Rare and Orphan diseases**. They collectively affect between **6 and 8% of the population** in a very heterogeneous manner.
- 🌍 Regardless of their heterogeneity, the FERs share common aspects, such as complex medical and social problems due to their serious implications and considerable burden on individuals and their families.
- 🌍 Studies showing the reality of people with EPOF in Spain, Germany, Slovakia and the UK report very similar experiences. (Federación Española de Enfermedades Raras, 2009; Budysh, Helms y Schultz, 2012; Ramljaková, 2013; Muir, 2016),

Some of the common factors experienced by people with Rare Diseases we have found:

- Unequal access to the healthcare system
- Struggling with inadequate social and health care
- Lack of adequate resources
- Poor scientific knowledge and little social understanding

Studies on Social Healthcare Needs

Information specific to Europe

- Federación Española de Enfermedades Raras (FEDER, 2009, 2018)
Spanish Federation of Rare Diseases
- Organización Europea para las EE.RR. (EURORDIS, 2016)
European FER Organization
- Rare Disease UK (2017).

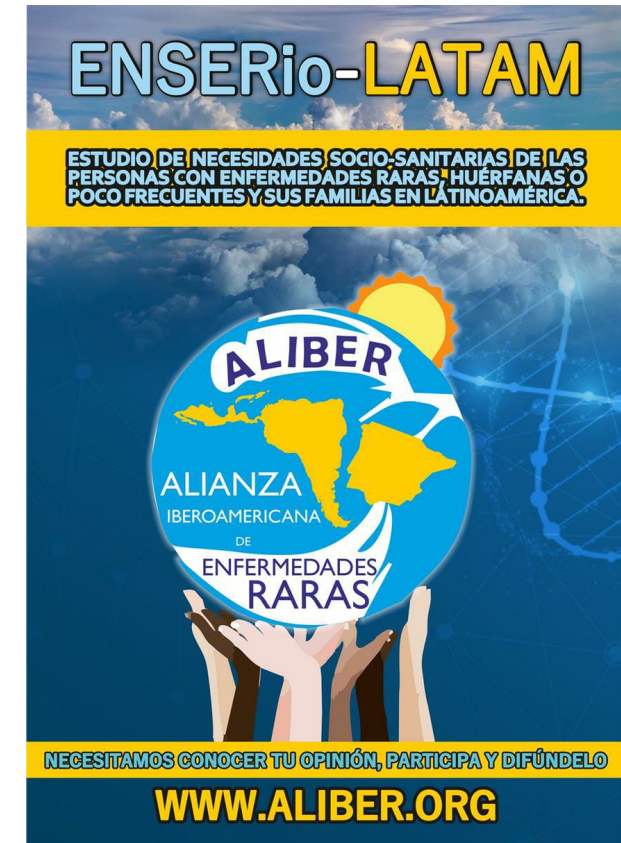
Information specific to Latin America

At present, Latin America does not yet have a detailed study of the circumstances and needs experienced by families with Rare Diseases. Being aware of these issues is essential to be able to deal with these diseases properly.

Training and research

In 2018, as part of the Strategic Line of Training and Research, ALIBER launched the Study of the Social and Health Needs of People with Rare Diseases and their Families,

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Proyecto ENSERio LATAM

Overall objective

- To learn more about the reality of the social and health needs of people with FER and their families in Latin America.

Specific objectives

- Outline the socio-demographic characteristics of people with Rare Diseases in Latin America
- Define the process to diagnose and treat Rare Diseases in Latin American countries
- Outline the impact Rare Diseases have on the health, day-to-day activities and general behavior of Latin American patients.
- Clarify the costs associated with Rare Diseases in Latinamerica.
- Outline the coverage of costs derived from the Orphan Disease by public and private health care and the patient and their family in Latin America.
- Identify the ways in which people with Rare Diseases in Latin America are affected in relation to social inclusion.
- Establish a list of healthcare professionals who work in the field of Rare Diseases in various countries in Latin America.
- Establish a list of referral centers or care units for Rare Diseases in Latin America.

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Instrumento y dimensiones analizadas

Specifically designed questionnaire in:

- ✓ Spanish
- ✓ Portuguese
- ✓ Brazilian Portuguese



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Methodology

The study is based on **research techniques with primary data**, i.e. the data is directly gathered from the participation of people with Rare Diseases and their families by answering the questionnaire, i.e. by applying a **quantitative technique**.

However, secondary sources (statistical and bibliographic) are also analyzed, in order to frame the research and complement the primary data that has been gathered.

Stages: main actions

1st stage: (2018): Design of the questionnaire, identification of the sample, preparation for the reception of the questionnaires, testing of the questionnaire and design of the dissemination campaign.

2nd stage (2019): Distribution of the questionnaires, encouragement of the patient organizations belonging to ALIBER to collect information, reception of questionnaires, coding and tabulation of results, preliminary analysis (as of December 31st: 1,087 valid questionnaires).

3rd stage (2020- March 2021): Further distribution of questionnaires, reception of the questionnaires, coding and tabulation of results, specific analysis writing the report, a global report, with data from all Latin American Countries and from participating countries. **Presentation of the results on World Rare Disease Day 2021 (28 February)**



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Scientific Committee y synergies

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The Project's Benefits

- Promotion of public policies and public and private health measures in accordance with the needs of people with Rare Diseases and their families.
- Creation and/or adaptation of specific health and social resources based on the needs identified in Latin America
- Help with the generation of country-specific records.
- Anticipate possible situations of need to tackle Rare Diseases in Latin American countries
- Identifying lines that should not be crossed when suffering from a Rare Disease.
- Establish synergies of collaborative work between countries, like the great alliance that Latin American countries form to front rare diseases.
- In conclusion:
 - **Contribution to the improvement of the quality of life of people affected by a Rare Disease through the explicit knowledge of their needs, covering not only clinical but also social aspects.**

Budget

PLANNED EXPENDITURE			
Human Resources			
Job	Gross Salary	Segu Social enterprise	Total
Service Coordinator (Full working day: 6 months)	€931,000	€288,610	€12,196
1 Service Technician (Half working day: 6 months)	€465,500	€144,305	€6098
Subtotal of Human Resources			€18,294
MATERIAL AND TECHNICAL RESOURCES			
Computer Assets and Equipment			€113,333
Promotion materials			€200,000
Software, office technology and Antivirus			€61,800
Subtotal Material and Technical Resources			€375,133
MANAGEMENT			
Telephone and ADSL			€160,000
Mail and Courier Service			€70,000
Insurance			€20,000
Subtotal of Management			€2500
EXTERNAL SERVICES			
Tax, Accounting and Labor Consultant			€150,000
Domain and Server Maintenance			€50,000
Subtotal of External Services			€2000
DIETS AND TRAVEL			
Diets and Travel			€150,000
Subtotal of Diets and Travel			€1500
OTROS			
Contingencies and others			€200,000
Subtotal of Other Costs			€2000
ENTIRE BUDGET			€3,004,548



Member Entities of ALIBER

