



# STUDY OF NEEDS OF PEOPLE WITH LIPODYSTROPHY AND THEIR RELATIVES IN IBERO-AMÉRICA

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## INTRODUCTION

Lipodystrophies are a group of diseases characterized by the loss of adipose tissue. A classification can be made according to their etiology, as they can be congenital (or familiar) or acquired, or according to their anatomical location, as they can be generalized, partial, or localized. Based on their causes, they can be congenital (genetic) or acquired. Lipodystrophies are classified within the so-called infrequent pathologies with an estimated prevalence of affection in 1 out of 2000 people. That is why the lack of information on lipodystrophies is one of the most important consequences of the disease, producing ignorance and uncertainty in people and relatives that live with it. The absence of experts considered as a reference point in lipodystrophies triggers situations of instability in the family environment. The net of people which makes up the association of family members and people affected by lipodystrophies (AELIP) has been and in fact is the main driving force for change produced in the multidisciplinary approach of lipodystrophies in our country. With this social research project, AELIP aims to study the needs presented by people living with a lipodystrophy and their relatives as well as to know the degree of satisfaction of social and health resources that this association makes available to them. They are the axis and the driving force of the consolidation of an associative movement that we can define as being especially active in the public health.

## SUBJECTS AND TECHNIQUES

The study of needs was carried out by family members and people affected by lipodystrophy in Ibero- America (103 people), of which 88% were women and 12% were men between 25 and 50. The techniques used to achieve the research objectives are the following:

1. Analysis of documentation
2. Needs study (Survey)
  - 2.1 Current situation-Desired situation.
  - 2.2 Weaknesses and strengths.
  - 2.3 Social skills and decision making.
3. Evaluation of the study
4. Final conclusions

## RESULTS

1. Types of Lipodystrophies with more prevalence: **Berardinelli Seip syndrome, Partial family lipodystrophy type 2 Dunningan, and Barraquers Simons syndrome.**
2. Countries with the highest incidence of cases: **Spain, Colombia, Mexico, Venezuela, Argentina, and Peru.**
3. The socio-sanitary situation of the survey respondents was rated as improvable by **65%**.
4. **62%** of the survey respondents consider that the emotional support they receive from their relatives is good.
5. **74%** of the survey respondents state that as a result of the disease their social and personal relationships have changed, increasing social rejection.
6. **98%** of the survey respondents consider the information and guidance service in Lipodystrophies very important.
7. **73%** of respondents stated that they need a psychological support service for families and affected people.

## CONCLUSIONS

The need for multidisciplinary intervention in lipodystrophies should be considered as a social and health priority to improve the quality of life of individuals and families that coexist with any type of lipodystrophy in the world. Even more, if we take into account the nature of Lipodystrophies which are characterized, among other things, by dispersion and by low prevalence, the individual and isolated acceptance can be hardly ever successful.

The study concludes that the most important needs to be met are: Social and psychological support to patients, access to the treatment of recombinant human leptin, promote more family respite activities, obtain more information in the field of Lipodystrophies, a greater knowledge on the part of medical professionals for the diagnosis of the disease, information on aesthetic operations or to meet more people with the same type of disease.

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