

MANIFEST

WORLD LIPODYSTROPHY DAY 2026

Lipodystrophies are rare, serious, chronic and, in some cases, life-threatening diseases. They cause total or partial absence of adipose tissue and lead to severe metabolic complications, liver damage, systemic involvement and a profound physical, psychological and social impact.

Delayed diagnosis, lack of training and unequal access to treatment further aggravate the situation.



The International Association of Families and People Affected by Lipodystrophies (AELIP) requests and demands:

1. DIAGNOSIS WITHOUT DELAY

No more medical pilgrimages. Clear protocols for clinical suspicion and early referral must be established to avoid years of uncertainty and irreversible damage.

2. EFFECTIVE REFERRAL TO REFERENCE CENTRES

It is essential that all Autonomous Communities guarantee effective and swift referral to the CSUR for metabolic diseases, which includes the Lipodystrophy Reference Unit at the University Hospital Complex in Santiago de Compostela. The designation of a CSUR must translate into effective access.

3. SPECIFIC TRAINING

Lipodystrophies must be part of formal training in paediatrics, endocrinology and primary care. You cannot diagnose what you do not know.

4. INVESTMENT IN RESEARCH

Stable public funding is essential to research the genetic and molecular bases of these diseases and develop specific treatments.

5. INTERNATIONAL MAP OF EXPERTS

It is necessary to create an international registry and map of specialists to facilitate access to knowledge and reduce regional inequalities.

6. COMMITMENT OF SCIENTIFIC SOCIETIES

Scientific societies must systematically incorporate lipodystrophies into conferences, clinical guidelines, working groups and research programmes.

7. SUPPORT FOR THE EUROPEAN LIPODYSTROPHY CONSORTIUM

It is essential to maintain and strengthen institutional support for European networks working in research and clinical coordination.

8. EQUITY IN ACCESS TO ORPHAN DRUGS

Access to approved treatments must be equitable and not dependent on place of residence. Territorial equity is an obligation of the National Health System.

9. METRELEPTIN: EQUITABLE ACCESS

The Ministry of Health and the pharmaceutical company Chiesi are requested to resume negotiations to reach a price-reimbursement agreement for metreleptin, which is already available in other European countries.

10. EQUITY AND HEALTHCARE JUSTICE

Life, health and life expectancy cannot depend on a postcode or administrative decisions. Ensuring equal access to diagnosis and treatment is the responsibility of the healthcare system.

#WLD2026

#TreatmentEquity

#Lipodystrophy



RARE DISEASES INTERNATIONAL
A EURORDIS RARE INITIATIVE



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