31 ST MARCH

WORLD DAY OF LIPODYSTROPHIES – 31 MARCH –

WORLD DAY OF LIPODYSTROPHIES

#WLD2026
#TreatmentEquity
#Lipodystrophy

SEL

European consortium of lipodystrophies

RARE DISEASES INTERNATIONAL

AELIP

EURORDIS

alber
Alianza Iberoamericana de Enfermedades Raras

feder

www.aelip.co.uk

ASSOCIATION INTERNATIONAL OF RELATIVES AND PEOPLE AFFECTED BY LIPODYSTROPHIES - AELIP

WORLD LIPODYSTROPHY DAY 31 MARCH

WORLD LIPODYSTROPHY DAY

It was created in 2013 as a platform for developing benchmark activities and for undertaking, coordinating and promoting political and social actions in different parts of the world in collaboration with international country alliances.

In March, AELIP celebrates the most important awareness campaign of the year at an international level: World Lipodystrophy Day on 31 March.

This campaign is promoted by the European Organisation for Rare Diseases (EURORDIS) and the Spanish Federation for Rare Diseases (FEDER) and is carried out in coordination with the Ibero-American Alliance for Rare Diseases (ALIBER), Rare Diseases International (RDI), the Spanish Society for Lipodystrophies (SEL) and the European Consortium for Lipodystrophies (ECLIP).

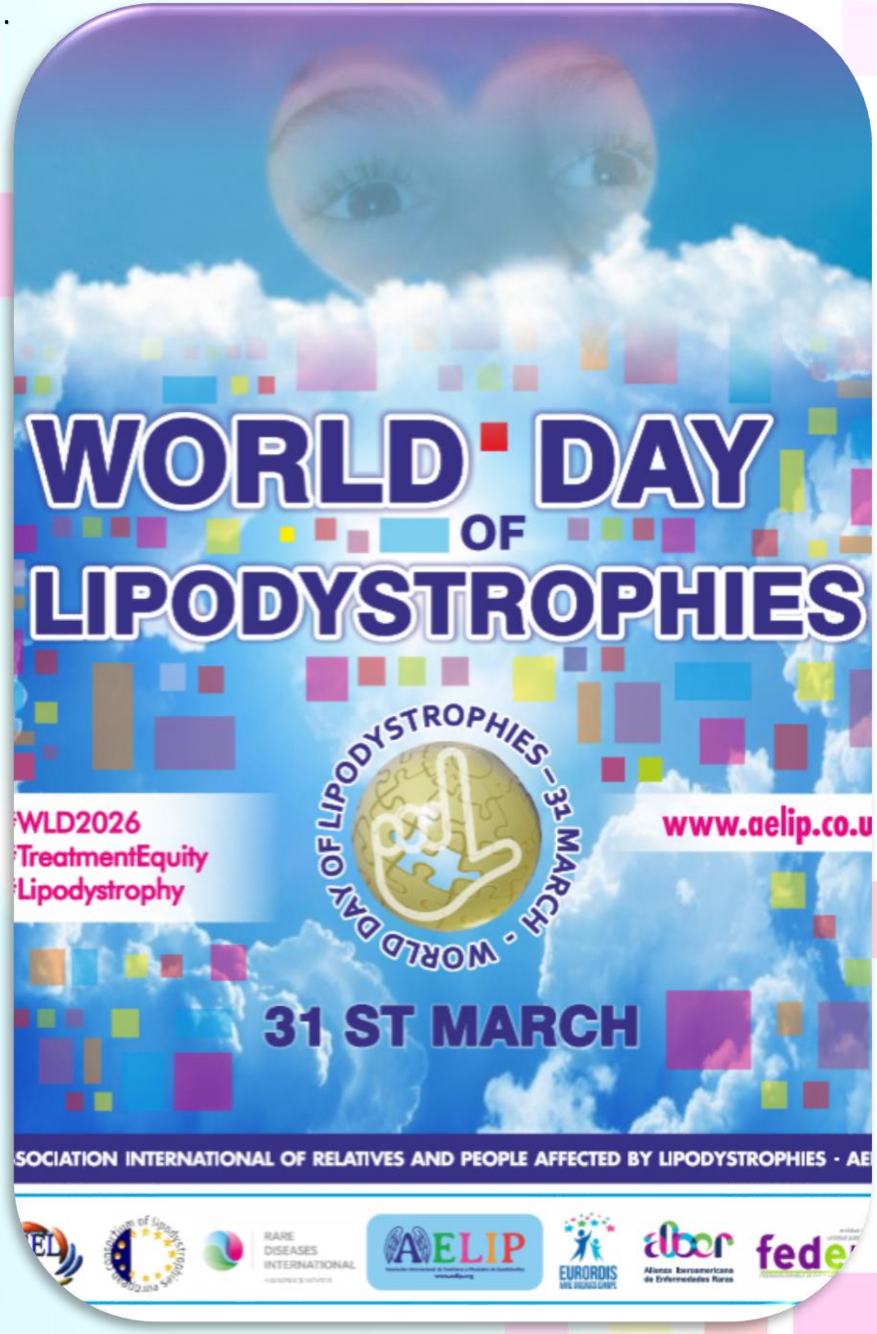
Is it fair that your life depends on your postcode?

31 March marks World Lipodystrophy Day in Spain, a date set aside to raise awareness of these rare diseases characterised by abnormal loss of adipose tissue and serious metabolic complications.This year, the campaign focuses on equitable access to metreleptin, the only treatment currently authorised for lipodystrophy, approved by the European Medicines Agency.

However, in Spain, public funding for this treatment is not guaranteed, which creates a worrying inequality among patients.Because when it comes to health, it shouldn't matter where you live.

Today, we are raising our voices for fair, equitable and barrier-free access to the only treatment available. For people with lipodystrophy. For their right to live

WORLD LIPODYSTROPHY DAY 31 MARCH



Aims and Objectives of World Day

- ✓ Among AELIP's objectives for this campaign:

- ✓ Raise awareness about the public health issues posed by lipodystrophies.
- ✓ Implement actions that help prevent the social isolation that those affected by lipodystrophies and their families often suffer.
- ✓ Carry out activities to disseminate information about the characteristics and particularities of lipodystrophies.
- ✓ Raise awareness in society about the physical, metabolic and emotional impact that lipodystrophies have on the lives of those affected.
- ✓ Coordinate actions with all parties involved: patients, public administration, health professionals, etc., to seek resources and improve care for those affected.
- ✓ Defend equity in access to treatment, especially metreleptin, the only drug authorised for lipodystrophies.
- ✓ Denounce regional inequality in access to treatment in Spain.
- ✓ Promote the right to fair healthcare, regardless of place of residence.

Why a symbolic gesture?

Because it is a distinctive element that encourages everyone to join the Campaign. It generates a feeling of unity and cohesion around people with lipodystrophies and exemplifies the conceptual idea of the Campaign in a simple and straightforward way. The origin of the gesture stems from support for lipodystrophy research.

What gesture are we going to promote?

Gesture: Campaign ‘L’ form an L with the thumb and index finger of your left hand What do we want to inspire? Why this gesture?

- This gesture symbolises the initial ‘L’ of the word Lipodystrophy
- It conveys a message of unity and support.
- It conveys positivity and a sense of victory.

WORLD LIPODYSTROPHY DAY 31 MARCH

WHAT ACTIONS WILL WE TAKE AT AELIP?

1. Request for adherence to the manifesto on lipodystrophy by local councils throughout the country.

On World Lipodystrophy Day, the manifesto drawn up by AELIP is a central part of the institutional action linked to this date. It is a strategic document whose objective is to convey to society, healthcare professionals and public authorities a clear, well-founded and collective position on the reality experienced by people affected by these rare diseases.

Its main function is to highlight the magnitude and severity of lipodystrophies, emphasising their chronic nature, their potential life-threatening risk and the profound physical, psychological and social impact they have. At the same time, the manifesto serves to raise awareness and highlight structural problems such as delayed diagnosis, lack of specialised training and inequalities in access to treatment.

In addition, the document acts as an advocacy and advocacy tool, as it formulates specific demands addressed to health institutions, public bodies, scientific societies and agents in the health field. These requests seek to promote real improvements in early diagnosis, referral to reference centres, research, international coordination and therapeutic equity. The manifesto not only informs, but also articulates the collective voice of patients, families and professionals, becoming a key instrument for promoting commitments, guiding health policies and moving towards a fairer, more specialised and accessible model of care.

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

2. Social media campaign

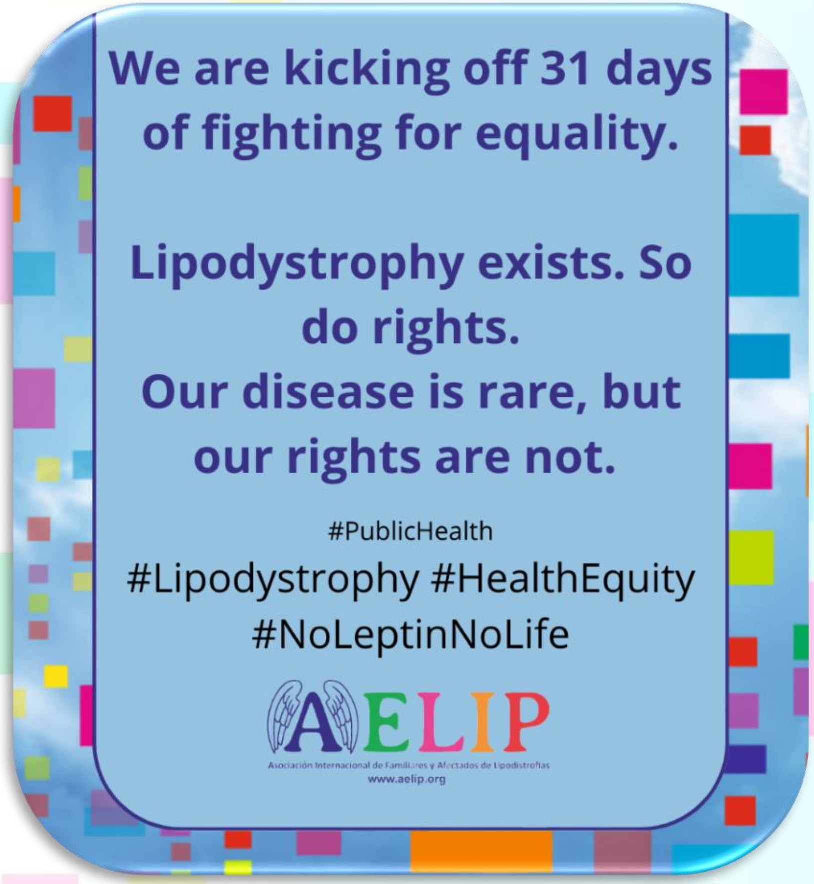
The main purpose of the social media campaign for World Lipodystrophy Day is to promote real change in the health and social situation of those affected, promoting equity in access to diagnosis, specialised care and treatment. Through awareness-raising and dissemination activities, the aim is to highlight the fact that lipodystrophies are rare, serious and often unknown diseases, whose invisibility contributes to delayed diagnosis and clinical deterioration.

The initiative also aims to raise awareness among society and institutional leaders that the rarity of a disease cannot justify inequalities in rights or healthcare, and that lack of access to therapeutic resources or trained professionals has direct consequences on the health and quality of life of those living with these conditions.

In this context, the campaign acts as a tool for social mobilisation and institutional advocacy aimed at generating commitment, promoting political decisions and moving towards a more just, accessible healthcare model based on effective equality.

#Lipodystrophy #HealthEquity

#NoLeptinNoLife



We are kicking off 31 days of fighting for equality.

Lipodystrophy exists. So do rights.
Our disease is rare, but our rights are not.

#PublicHealth
#Lipodystrophy #HealthEquity
#NoLeptinNoLife

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3. Visibility actions at sporting events broadcast on television.

The campaign's presence at televised sporting events transforms a symbolic gesture into a high-impact communication action, capable of amplifying visibility, reinforcing the legitimacy of the cause and accelerating social awareness of lipodystrophies.

#Lipodystrophy **#HealthEquity** **#NoLeptinNoLife**

4.Awareness campaign in primary and secondary schools through the story ‘Celia, an unusual princess’.

During the month of March, AELIP runs a programme of educational and awareness-raising talks in schools and colleges throughout Spain to mark World Lipodystrophy Day. The aim of this educational initiative is to raise awareness among students about these rare diseases, promoting knowledge, empathy and social awareness from an early age.

The sessions provide a clear and tailored explanation of what lipodystrophies are and what their medical and social implications are. As part of the activity, students learn about Celia's story through the storybook ‘Celia, una Princesa Poco Frecuente’ (Celia, a Rare Princess), an educational resource that facilitates understanding of the disease from a close and human perspective.

The talks also highlight the fundamental role of scientific research as a driver of hope and improved quality of life for affected individuals and their families around the world.

The main objective of this programme is to give a voice and visibility to lipodystrophies, to those who live with them, and to the need to promote scientific knowledge and social commitment as essential tools for advancing towards greater health equity.

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5.Turquoise lighting in public spaces in Spain

- Every 31 March, various Spanish cities join in the commemoration of World Lipodystrophy Day by illuminating iconic buildings, town halls, fountains and monuments in turquoise.

- This symbolic action seeks to:
- • Raise awareness of these rare and little-known diseases.
- • Sensitise the population to early diagnosis.
- • Show institutional support for patients and families.
- The decorative lighting is usually coordinated between AELIP and local authorities and cultural or public health departments. Although the participating buildings change every year, the initiative maintains a consistent message: to turn urban spaces into a visual platform for social awareness.

6.AWARENESS-RAISING AND FUNDRAISING ACTIVITIES

We will organise visibility, awareness and fundraising activities such as the 'EVENING FOR LIPODYSTROPHY' and the 'III SOLIDARITY FOOTBALL TOURNAMENT' among others.

VELADA
POR LAS
LIPODISTROFIAS 2026
"DÍA MUNDIAL TOTANA"

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VIERNES 6 DE MARZO A LAS 20:30H
PLAZA BALSA VIEJA

COLABORAN
Ayuntamiento de Totana
Ilustre Cabildo Superior de Procesione

III JORNADA DE CONVIVENCIA SOLIDARIA DE FÚTBOL BASE
Centros educativos de Totana y Paretón

POLIDEPORTIVO MUNICIPAL 6 DE DICIEMBRE TOTANA
SÁBADO 28 MARZO 2026

CATEGORIAS (MASCULINA Y FEMENINA):
Prebenjamin 1° y 2° primaria
Benjamin 3° y 4° primaria
Alevín 5° y 6° primaria
Infantil 1º y 2º ESO

INSCRIPCIONES:
Polideportivo 6 de Diciembre
Martes, Jueves y Viernes de 16:30 a 18 horas.
Complejo Valle Guadalentín Paretón
Lunes, Miércoles y Viernes de 16:15 a 17,30 horas.
Hasta 4 de marzo de 2026
Más Información: Andrés 636477030

ORGANIZA
P.B. TOTANA
PEÑA BARCELONISTA TOTANA
ASOCIACIÓN DEPORTIVA SANTA EULALIA PBTO TOTANA

COLABORA
d´genes
Asociación de Enfermedades Raras
AELIP
Asociación Internacional de Familiares y Afectados de Lipodistrofias
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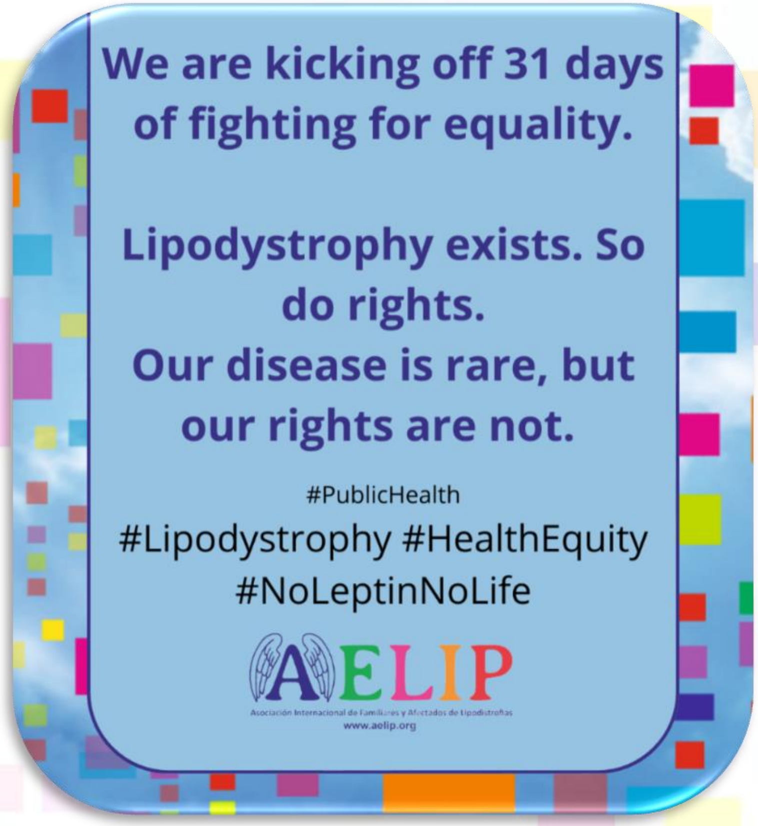
How can I support World Lipodystrophy Day?

1. Share the stories of the 31 days of the campaign daily on social media

Share the stories of these 31 days on social media with the hashtags

Lipodystrophies exist, rights do too.



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#Lipodystrophy **#HealthEquity** **#NoLeptinNoLife**

WORLD LIPODYSTROPHY DAY 31 MARCH

2. Ask your local council to light up a landmark building, town hall or fountain in turquoise on 31 March and upload a photo to social media with the hashtags con los hashtags **#Lipodystrophy** **#HealthEquity** **#NoLeptinNoLife**

3. Support and share the manifesto for Lipodystrophies 2026

MANIFEST

WORLD LIPODYSTROPHY DAY 2026

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#WLD2026 #TreatmentEquity #Lipodystrophy

4. Upload your photo with the L gesture (using your thumb and index finger) to FACEBOOK or INSTAGRAM with the hashtags

#Lipodystrophy **#HealthEquity**

#NoLeptinNoLife

WORLD LIPODYSTROPHY DAY 31 MARCH

CALENDAR OF SCHEDULED ACTIVITIES FOR WORLD DAY

TURQUOISE LIGHTING OF EMBLEMATIC BUILDINGS AND ADHERENCE TO THE DECALOGUE BY PLENARY SESSIONS (31 MARCH)

TOTANA, ALHAMA DE MURCIA, CARTAGENA, MURCIA, CONSEJERÍA DE SALUD RM, MOGUER, HUELVA, RUBÍ, SANTIAGO DE COMPOSTELA, VIGO.

1. TRAINING ACTIVITIES

TOTANA

- ✓ THURSDAY, 26 FEBRUARY (SAN JOSÉ SCHOOL)
- ✓ MONDAY, 9 MARCH (JUAN DE LA CIERVA SECONDARY SCHOOL)
- ✓ TUESDAY, 10 MARCH (JUAN DE LA CIERVA SECONDARY SCHOOL)
- ✓ TUESDAY, 17 MARCH (CEIB EL PARETÓN)

MOGUER

- ✓ TUESDAY, 24 MARCH (IES GARFIAS MOGUER)

ACTIONS IN INTERNATIONAL DELEGATIONS

- ✓ **ARGENTINA,** REPLICATE DECALOGUE AND CAMPAIGN
- ✓ **PORTUGAL,** REPLICATE DECALOGUE AND CAMPAIGN
- ✓ **PERU,** REPLICATE DECALOGUE AND CAMPAIGN
- ✓ **NETHERLANDS**, REPLICATE DECALOGUE AND CAMPAIGN

2. VISIBILITY ACTIONS

TOTANA

- ✓ FRIDAY, 6 MARCH “EVENING FOR LIPODISTROPHIES”
- ✓ SATURDAY, 28 MARCH “III DAY OF SOLIDARITY AND FRIENDSHIP IN YOUTH FOOTBALL”
- ✓ 23 TO 31 MARCH EXHIBITION OF BANNER FOR WORLD LIPODYSTROPHY DAY ON THE FACADE OF THE SENIOR CENTRE
- ✓ MARCH HIKING ROUTE - ANDARINES TOTANA

MURCIA

- ✓ 23 MARCH TO 31 APRIL EXHIBITION OF BANNER FOR WORLD LIPODYSTROPHY DAY ON THE FACADE OF THE REGIONAL HEALTH MINISTRY OF MURCIA
- ✓ SATURDAY 28 MARCH ‘UCAM BASKET- BILBAO BASKET’
- ✓ 5 APRIL ‘REAL MURCIA VS ATLETICO DE MADRID B’

#Lipodystrophy

#HealthEquity

#NoLeptinNoLife