



# MANIFESTO

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Lipedema is a global health problem that affects people worldwide, mainly but not exclusively women. The literature has shown both limited and conflicting data regarding the prevalence of lipedema.

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Lipedema is a chronic and potentially progressive disease of the connective tissue, which is often painful. It is a fat disorder that can cause severe deformity and disability, psychological and economic burdens.

3

Most health professionals are not fully aware of the disease, or its signs and symptoms, causing people with lipedema to suffer for many years before they obtain a diagnosis and begin treatment. Lipedema can be mistaken for obesity, lymphedema or a non-pathological disfigurement/excessive cellulite.

4

There remains low public awareness about the health impact and variation of different fat disorders, which has a significant impact on the lives of people with lipedema and the stigma they face. Access to appropriate and timely treatment is often limited and patients frequently find themselves blamed for their condition, or blame themselves.

5

There is no definitive cure for lipedema yet. However, it can be treated to reduce symptoms, maintain mobility, and improve quality of life while slowing potential disease progression. People with lipedema need access to high-quality multidisciplinary specialised centres and experienced healthcare professionals in order to receive appropriate treatment, covering physical, psychological and social care.

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There is a deep unmet worldwide need to educate and support individuals affected by lipedema, including family members and caregivers, on this medical condition and the most effective self-management to improve their quality of life.

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Medical research efforts to find a cure for lipedema and to optimize treatments are lacking sufficient funding, in comparison with diseases of similar magnitude and severity.

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Worldwide research should focus on: quality of life, nutritional guidance, management of comorbid diseases, techniques to reduce inflammation and fibrosis, physical therapies and compression effects, earlier diagnosis to allow for intervention and education, psychosocial support, as well as pre- and post-surgical protocols to improve care and medium- to longer-term outcomes.

9

Patient empowerment, defined by the World Health Organisation as "a process through which people gain greater control over decisions and actions affecting their health", is a key theme within global health and social care strategies. Lipedema Patients' Associations play a crucial role partnering with professionals in Evidence Based Medicine, shifting the focus from the disease itself to people living with lipedema.

**The organisations below support June 11<sup>th</sup> as World Lipedema Day and call for the attention of politicians, policy makers, health care professionals, researchers and the general public towards the needs of those who live with, or who are at risk of developing, lipedema. We ask for increased funding for research, involving patients in determining research priorities, educational programs for healthcare professionals, and improved access to specialised care for those living with lipedema.**

**Lipoedema**  
Charity No 1181312  
**UK**



**ANDLINF**  
Associação de Doentes  
Patient Association



**DALYFO**  
Dansk Lymfødemed Forening

