AMERICAN LIPEDEMA ASSOCIATION™

**POSITION PAPER**
**Proposed Renaming of Lipedema to Lipalgia Syndrome**
Adopted November 2026

On September 10, 2026, the International Lipoedema Association (ILA), an organization based in Denmark, announced that its board had endorsed renaming lipedema (spelled lipoedema in Europe) to *lipalgia syndrome*. **The American Lipedema Association (ALA) does not support this change.** This paper explains why, and describes the process we believe should guide any future change to the disease name.

## Why Lipedema Remains the Most Appropriate Name for the Disease

**Lipalgia names a symptom, not a disease.** Many conditions cause painful fat tissue. Lipedema can cause lipalgia, but not all lipalgia is lipedema.

**Lipohyperplasia dolorosa (LiDo) is an incomplete description.** Both more fat cells and larger fat cells contribute to the disease, and pain alone does not define it.

**The evidence does not support "no edema."** Sodium magnetic resonance imaging (MRI) studies and responses to decongestive therapy point to a tissue-fluid component that deserves further study.

**The biology is still emerging.** Inflammation, vascular and lymphatic dysfunction, tissue remodeling, and fluid handling may all contribute. A name should not get ahead of the science.

**Renaming now would set back recognition and access to care.** Lipedema has an ICD-11 code, national codes in countries such as Germany, and new US codes that take effect October 1, 2027. A second name would confuse patients, clinicians, and insurers just as those codes arrive.

**Any future name should come from international consensus.** That process should include clinicians, researchers, and patient organizations, and should follow research that identifies the causes of the disease.

**Bottom line: Lipedema remains the most appropriate and inclusive term. We should advance our understanding of the disease before we change its name.**

## Introduction

The ILA announced that its board unanimously endorsed the new term, which it says reflects the condition's "defining clinical symptom: pain." ILA President Gabriele Erbacher stated that the condition "is neither an oedema nor a lymphatic disorder." Lymphoedema Wales adopted the term in 2023. The ILA reports that the Földi Clinic in Germany has since followed, as has Klose Training, one US organization that trains clinicians for the Certified Lymphedema Therapist (CLT) credential (ILA, 2026). Others have proposed a different name, *lipohyperplasia dolorosa* (LiDo).

We share the ILA's goal of naming this disease accurately. We agree that pain is a central feature and that lipedema is distinct from lymphedema. We differ on the evidence and on the timing. Both proposed names describe selected features of the disease at a moment when research is still revealing how it works (Cifarelli, 2025).

Open questions remain. What causes the abnormal fat accumulation? What drives pain, swelling, heaviness, and loss of function? What roles do inflammation, blood vessels, lymphatic transport, and tissue fluid play? Our terminology should reflect what we know today without committing early to one explanation.

### 1. Lipalgia Describes a Symptom, Not a Distinct Disease

*Lipalgia* means pain in fat tissue. It does not identify a cause or a disease process. Painful fat under the skin occurs in many conditions, including panniculitis and erythema nodosum, and in infectious, autoimmune, medication-related, and cancer-related disorders.

A patient can accurately be described as having lipalgia secondary to lipedema. That phrasing keeps the disease and its symptom distinct. Adding "syndrome" signals a cluster of findings, but the name still points to pain alone.

Replacing the disease name with a symptom name would trade diagnostic specificity for a broader label. Patients with different diseases could end up grouped together. That would complicate clinical communication, research classification, and the development of disease-specific treatments.

Pain clearly matters in lipedema. The question is whether pain alone defines the disease, and it does not.

### 2. Lipohyperplasia Dolorosa Is an Incomplete Description

LiDo has a reasonable clinical basis because it names two real features: abnormal fat accumulation and pain. It has three limitations.

**First, hyperplasia describes only part of the fat tissue changes.** Hyperplasia means more fat cells; hypertrophy means larger fat cells. Both appear to contribute in lipedema, along with altered fat cell development and remodeling of the surrounding tissue. Researchers have not yet established how much each process contributes.

**Second, the mechanisms of pain are still under study.** They may involve inflammation, changes in sensory nerves, mechanical tissue changes, small blood vessel abnormalities, and fluid dynamics.

**Third, LiDo leaves out other systems that may be involved.** These include blood vessels, lymphatic transport, inflammation, connective tissue, and fluid handling. Ishaq et al. (2022) found disrupted cell-signaling networks in lipedema tissue, which points to changes beyond fat accumulation alone.

LiDo may ultimately prove accurate. That conclusion should follow a better understanding of the disease, not come before it. A more descriptive name is not the same as a name shown to reflect the disease mechanism.

### 3. The Evidence Does Not Support "No Edema"

We agree that lipedema is not lymphedema. We disagree that current evidence rules out a tissue-fluid component. Lipedema usually lacks the pitting edema seen in some other conditions, but pitting is a physical

exam finding. Tissue sodium, water-sensitive MRI measurements, and fluid clearance are measurable, and they can be abnormal without pitting.

**Sodium MRI shows measurable tissue differences**

Crescenzi et al. (2018) found higher sodium in women with lipedema than in matched controls. Skin sodium averaged 14.9 versus 11.9 mmol/L, and sodium in the fat under the skin averaged 11.9 versus 9.4 mmol/L. Crescenzi et al. (2020) extended these measurements to the arms and legs.

Nöll et al. (2026) studied 15 women with lipedema (five each at stages I, II, and III), 13 women with lymphedema, and five healthy controls. Women with lipedema had higher sodium than controls in skin (17.7 vs. 12.3 mmol/L), fat under the skin (13.6 vs. 8.2), and muscle (23.1 vs. 15.2). Skin sodium rose with disease stage ($r = 0.78$) and independently predicted pain scores.

**Fluid-directed treatment changes these measurements**

In the same study, women with lipedema received one 60-minute session of manual lymphatic drainage (MLD). Sodium in the fat under the skin fell from 13.6 to 11.2 mmol/L. Water-sensitive MRI values in skin and fat also fell. Median pain on a 0–10 scale dropped from 2 to 0 ($p = 0.007$).

The drop in pain tracked the drop in fat sodium ($r = 0.52$, $p = 0.048$), while fat fraction did not change significantly. MLD does not remove fat in an hour. These results point to a short-term shift in tissue sodium and water that came with less pain.

Women with lymphedema, included as a comparison group, showed a similar pattern after MLD. Their median pain also fell from 2 to 0 ($p = 0.039$). The two diseases remain distinct, but both appear to share measurable changes in tissue sodium and water that respond to fluid-directed care.

Clinical trials point the same way. Atan and Bahar-Özdemir (2021) randomized women with severe lipedema to complete decongestive therapy plus exercise, pneumatic compression plus exercise, or exercise alone. Adding complete decongestive therapy significantly improved limb volume, pain, and physical function. Many patients also report less pain, heaviness, and tightness with compression and other decongestive care.

**What this evidence does and does not show**

These studies have real limits. The Nöll study was small, measured one slice of the calf, and tested a single session. Baseline pain was low, and controls did not receive MLD. Time lying down may also have affected sodium. Higher sodium alone does not prove excess water, so sodium findings must be read alongside tissue composition and water content. More research is needed across disease stages and lipedema types.

The evidence does not show that every patient has clinically significant edema, or that fluid explains every symptom. It does challenge the claim that no fluid component exists. A model that excludes tissue fluid needs to explain why sodium, water-sensitive MRI values, limb volume, and pain change after fluid-directed treatment. We invite the ILA and the wider research community to study this question together.

## 4. Surgical Results Point to a Complex Disease

The LIPLEG trial (Podda et al., 2026) randomized 410 women with lipedema at 11 German centers to liposuction or conservative therapy. At 12 months, 68% of the liposuction group reported a meaningful

reduction in leg pain, compared with 8% of the conservative therapy group. The surgical group also improved in physical functioning and quality of life.

These results confirm that diseased fat tissue plays a central role in lipedema. They also show a layered picture. Restored mobility and function may have contributed to pain relief alongside fat removal. Follow-up at 36 months is under way and will show whether the benefits last. None of this supports defining the disease by a single feature.

## 5. Renaming Now Would Set Back Recognition, Education, and Access to Care

In the United States, lipedema is not well known, and medical schools do not regularly teach it. Three US organizations are working to change that: the ALA, The Lipedema Society (a medical provider society), and the Lipedema Foundation.

Together we are working to educate patients and providers on what lipedema is and how to recognize it. We are asking insurers to cover comprehensive treatment, including MLD, compression, and lipedema reduction surgery. We are also preparing clinicians to adopt the new US lipedema codes in ICD-10-CM, the US version of the International Classification of Diseases, which take effect October 1, 2027.

A second name would muddy all three efforts at the moment they come together. A clinician could learn “lipalgia syndrome” in training and then see “lipedema” in the coding system. Insurers writing coverage policies would face two names for one disease. Patients searching for answers would find both.

This split has already begun in US clinical training. Klose Training has adopted the new term, while other US organizations that train clinicians for the CLT credential have not. Therapists could learn different names for the same disease depending on where they trained. Those therapists then treat patients and document care in a coding system that uses “lipedema.”

The ILA states that diagnosis, coding, and access to treatment are unchanged, and we take that commitment seriously. The codes themselves, however, carry the current name: ICD-11 code EF02.2 (Lipoedema), Germany’s codes E88.21 to E88.24, and the new US codes (Lipedema Foundation, 2026). When the disease name and the code name differ, every clinician, coder, and insurer must bridge that gap. Where awareness is still low, that gap falls on patients.

The international community has not called for this change. The Lipedema World Alliance includes most of the world’s lipedema patient organizations, the ALA among them, along with researchers, clinicians, and other health organizations. Its 2026 Delphi consensus (Kruppa et al., 2026) offers a shared framework for defining and managing the disease. The Alliance has not recommended changing the disease name or the ICD-10 or ICD-11 codes.

Disease recognition takes years to build. Securing lipedema-specific codes required sustained work by patients, clinicians, and advocates in many countries. A new name would not automatically carry that progress with it. We should build on what has been achieved rather than risk it.

## Conclusion: The Path to Any Future Name

Lipedema names a recognizable clinical disorder without committing to a single mechanism. Lipalgia syndrome names one symptom that occurs in lipedema and many other conditions. LiDo names two features but leaves out others. These terms are not interchangeable.

Research may one day identify distinct biological subtypes or causes that justify more precise terminology. That would be a welcome step in disease classification. It should come through an international consensus process that includes clinicians, researchers, and patient organizations. That process should begin once research uncovers the causes of the condition, not before.

Until then, our shared priorities should be to keep diagnosis clear, advance the science, and protect the recognition that patients, clinicians, and advocates have worked hard to achieve. **We are not ready to abandon the term lipedema.** We invite our colleagues at the ILA and around the world to build a fuller, evidence-based model of this disease together.

**About the American Lipedema Association**

The American Lipedema Association is a 501(c)(3) nonprofit organization dedicated to empowering lipedema patients in the United States. We are a community of individuals affected by lipedema, along with medical professionals, researchers, and advocates, united in raising awareness and understanding of this underdiagnosed loose connective tissue disorder. EIN 99-3365909. www.AmericanLipedemaAssociation.org

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