



MILKEN INSTITUTE CENTER FOR STRATEGIC PHILANTHROPY

A Giving Smarter Guide To Accelerating Research Progress

GIVE SMARTER



An Executive Summary

LIPEDEMA

Lipedema is a chronic condition that occurs almost exclusively in women and manifests as symmetrical buildup of painful fat and swelling in the limbs, sparing the hands and feet. A critical issue is the poorly understood disease biology, which for diagnosed patients results in limited treatment options that, at best, ameliorate the symptoms of lipedema. Individuals who suffer from the disease are further impacted by the absence of diagnostic tools, the lack of public and medical awareness of lipedema, and the stigma associated with weight gain. As a result, the true number of women with lipedema, or its epidemiology, is unknown.

Braving these challenges is an active, numerous, and engaged patient community eager to participate in lipedema research. Supported by equally devoted caregivers and researchers, the lipedema field presents an immense opportunity for scientific and medical advancements. To capitalize on this potential, the Lipedema Foundation and the Milken Institute's Center for Strategic Philanthropy convened leading stakeholders to discuss the current state of lipedema science and identify the key philanthropic research opportunities to advance the field.



MILKEN INSTITUTE
CENTER FOR STRATEGIC PHILANTHROPY

The Milken Institute Center for Strategic Philanthropy works to maximize return on philanthropic investment by ensuring that innovation used to address one social issue is translated to another, best practices and metrics guide new and existing giving programs, and resources are invested to optimize outcomes.

philanthropy.milkeninstitute.org

Patients report that onset of lipedema symptoms coincided with puberty, however, the average age of diagnosis was 44 years old.

Little is known about how and why lipedema develops in a patient. Although the disease is reported to occur during puberty and other periods of hormonal changes, why this happens is not understood. The painful fat and swelling in some patients can be so debilitating that their mobility is impaired; yet what drives these symptoms is unknown. Psychosocial issues are also prevalent in women with lipedema, contributing to health burden and complexity of disease management. Furthermore, many patients develop the disease alongside obesity; however, diet, exercise, and weight loss surgery have limited effect on lipedema fat. Although the lack of disease biology is staggering, philanthropic investments in research can leverage the desire of patients to participate in studies to improve their and the entire field's understanding of lipedema. The convergence of multiple scientific topics around lipedema indicates that addressing these gaps in research will also improve the understanding of hormone, pain and edema, mental health, and metabolic biology.

There are no diagnostic tools or tests for lipedema. Diagnosis of lipedema involves a clinical assessment and discussion of the individual's medical history, a process

that is difficult to scale within the current healthcare system. The absence of diagnostic tools to streamline or confirm a clinical diagnosis is a key unmet need, which if addressed by philanthropy, has the potential to dramatically change the trajectory of the disease. Investing in research efforts to advance novel imaging technologies to diagnose lipedema is a promising research avenue that would simultaneously benefit individuals who suffer from the disease and healthcare providers unfamiliar with the condition.

The public and medical community are not aware of lipedema. Lipedema was initially described in 1940, yet little knowledge about the disease has permeated the general public, with a concomitant lack of mention in the educational curriculum of medical trainees. Addressing this challenge will require philanthropic efforts to define the disease from a basic, clinical, and diagnostic perspective. A key philanthropic opportunity is support for a lipedema patient registry linked to a tissue biorepository. This effort has the potential to generate and support the needed disease research, while engaging patients as partners in understanding the science of lipedema.

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