



LIPEDEMA
FOUNDATION

POSITION SPECIFICATION

Executive Director

Greenwich, CT

www.lipedema.org

ABOUT THE OPPORTUNITY:

The new Executive Director will be an entrepreneurial and driven professional who will serve as a strategist, champion, and leader for the Lipedema Foundation (“LF”). The Executive Director will partner closely with the Founder/Current Executive Director, the Chief Science Officer, and the broader team to design and execute LF’s strategy and plan. This is an exciting moment to be a part of something truly unique in women’s health and to guide the Foundation in ensuring collective awareness, accessible diagnostic tools, and available patient treatments for lipedema.

More specifically, the Executive Director is charged with the following key responsibilities:

Strategist:

- Develop and execute a strategic plan in conjunction with the Founder, Chief Science Officer, and team with a focus on scientific/medical research, grant-making, awareness, and organizational and systems growth.
- Prioritize and balance gaps and opportunities; lay the groundwork for complex, future large-scale research projects and key operational and organizational projects that serve the mission.

Champion:

- Significantly grow awareness around lipedema among multiple stakeholder groups including researchers, surgeons, doctors, therapists, and the general public.
- Serve as one of the thought leaders, public faces, and ambassadors for the Foundation to the public and partners via conferences, retreats, webinars, and other opportunities.

Leader:

- Lead a small team of professionals and partner closely with the Founder in a culture that promotes a high level of collaboration, mutual respect, humility, and excellence.
- Build a network of collaborative scientific investigators, clinicians, and educators to extend the Foundation’s reach as well as work to formalize LF’s Advisory Board and its governance.

ABOUT THE SUCCESSFUL CANDIDATE:

LF seeks a strategic leader with superior communication, team management, and relationship building skills. The new Executive Director will have a systematic approach to developing and driving robust strategies and plans and a deep interest in and passion for women’s health.

Key Experiences and Attributes Include:

- An energetic leader with a minimum of 10 years of leadership experience from disease-focused foundations, non-profits, start-ups, or corporate sector; an understanding of collaborative grants and associated processes required.

- A critical thinker, able to create a vision, develop a plan, marshal resources, and execute on objectives utilizing a proactive and entrepreneurial mindset.
- Open, inclusive, adaptable, and motivating with experience managing an efficient and collaborative team.
- Experience creating and implementing top-notch systems, operations, processes, and programs as well as an understanding of boards and governance.
- Eloquent and poised to serve as an ambassador as well as distill complex scientific information into clear and compelling messages.
- Personable, humble yet confident, and a natural relationship builder able to seamlessly transition between scientists, patients, and physicians.
- Organized in both the breadth of the big picture and executing the depth of the small details with the self-directed drive to ensure accountability and success.
- Innately motivated by the mission and goals of LF and excited to be a continuous learner around lipedema.

EDUCATION: Bachelor's degree required. MBA, MPH or MS preferred. PhD a plus.

TRAVEL: Approximately 25% travel; ability to work one day a week from home or Manhattan.

ABOUT LIPEDEMA:

Lipedema is a female condition where irregular fat builds up in the arms and legs, sometimes with swelling and pain. It can be mistaken for obesity or lymphedema. It is widespread (affecting >1% of adolescent and adult women), but research and treatments are lacking because of limited awareness and because there is no diagnostic test. Adolescent and adult women affected. Key awareness statistics show large growth in recent years, such as 200+ social media groups and pages and the YouTube channel made by LF founder having over 630,000 views. Currently there is no proven diagnostic test (gene, imaging, blood or other biomarker). Initial small-scale research is showing interesting results and you can read more at <https://www.lipedema.org/research-impact>.

ABOUT THE LIPEDEMA FOUNDATION:

LF is a private, non-fundraising foundation founded by Felicitie Daftuar that has funded 30 grants with a variety in institutions, locales, and PI experience level. It intentionally seeks truly collaborative researchers because of the early stage of research. LF remains small and focused by outsourcing non-core functions (marketing/SEO, legal, accounting, IT, software) and having an intentionally narrow scope. LF will continue to focus on increasing awareness and supporting research innovations in diagnosis and treatment of lipedema as well as innovations in the disease-space such as developing a patient registry and hosting scientific retreats around lipedema.

COMPENSATION: Salary and benefits are competitive and commensurate with experience.

The Lipedema Foundation is an Equal Opportunity Employer and encourages candidates of all backgrounds to apply for this position.

Please email cover letter and resume or nominations in confidence to: LF@sandlersearch.org