



LIPEDEMA  
FOUNDATION

## POSITION SPECIFICATION

### Chief Science Officer

Greenwich, CT

[www.lipedema.org](http://www.lipedema.org)

#### ABOUT THE OPPORTUNITY:

The Lipedema Foundation (LF) seeks an experienced science professional to design, execute, and manage the Foundation's evolving research agenda addressing current, early stage science in lipedema treatments and diagnostics. Reporting to the Executive Director, the Chief Science Officer will partner closely with the Founder to direct and implement a robust grants program of about \$2 million annually that includes assessing and improving upon strategies for research learnings and recommendations as well as ongoing grantee partnerships.

#### *Key Responsibilities:*

- Develop and execute the lipedema research roadmap, a multi-year strategic plan that moves the research community forward in identifying treatments and accessible diagnostic tools for the disease.
- Serve as an unbiased scientific representative and spokesperson for the Foundation, communicating complex science in a clear, articulate, and digestible manner.
- Grow the lipedema network and its network density by hosting scientific retreats for LF, attending and presenting at scientific/medical conferences, developing new collaborations, and connecting relevant topics across specialties in the medical and scientific communities.
- Partner with the Executive Director and Founder to formalize LF's Advisory Board(s).
- Facilitate and execute the grant lifecycle process with grantees including:
  - Evaluate projects, learnings, and outcomes to create recommendations for the research roadmap;
  - Serve as a thought partner with grantees in each step of the grant making process;
  - Identify opportunities to promote and elevate grantees' work; and
  - Update the grant review process and assessment tools to limit reviewer bias.
- Manage and appropriately utilize data and associated processes: drive data sharing agreements and coalesce project data from across multiple coordinated and disparate projects, the IRB process, and the patient registry.
- Drive the quality of research performed and help design projects that are published in respected journals.
- Manage program budget and future staff; partner with all staff as a senior team member.

#### ABOUT THE SUCCESSFUL CANDIDATE:

LF seeks a Chief Science Officer who brings an entrepreneurial, data-driven, rigorously scientific, and collaborative approach to grant making and partnerships as well as medical/scientific research, healthcare, and grant making expertise. The successful candidate will be proactive and strategic, able to see the broad research picture and formulate a plan to drive towards objectives. A deep interest in and passion for women's health is a must.

## ***Key Experiences and Attributes Include:***

- Experience of at least 10 years in medical research or healthcare sector with a PhD in a discipline relevant to lipedema; laboratory management experience a plus.
- Experience taking other scientific/medical-research non-profits through major startup initiatives and research roadmap building, such as maximization of registries' utility, multi-institution collaborations, a plus.
- A strategic perspective for developing a research roadmap while identifying and executing on crucial details.
- The ability to assess, synthesize, and communicate a vast spectrum of scientific research, from basic, translational, and clinical research, across multiple specialties.
- A partnership and relationship builder able to convene and connect disparate stakeholders as well as the gravitas and charisma to serve as a spokesperson for LF and lipedema.
- Understanding of and ability to implement best practices for grant making from ideation to proposal development to ongoing assessments to final outcomes and deliverables.
- Excellent communication skills with ability to synthesize complex information and transform complex issues into understandable, digestible, and persuasive messages.
- Collaborative and open with stakeholders such as grantees, scientists, partners, and more.
- Skilled in employing innovative and evolving technology and software to keep data secure.
- An independent, self-starter with strong bottom-line orientation, a track record of exceeding goals, and a can-do attitude with a willingness to jump into projects as needed.
- Innately motivated by the mission and goals of LF as well as being a part of a highly professional and inclusive team.

## **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. 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.

*LF is an Equal Opportunity Employer and encourages candidates of all backgrounds to apply.*

**Please email cover letter and resume or nominations in confidence to: [LF@sandlersearch.org](mailto:LF@sandlersearch.org)**