

The background of the slide is a night-time photograph of the St. Louis skyline. The Gateway Arch is the central focus, illuminated and arching over the city. Other buildings are lit up, and their lights reflect on the water in the foreground. The sky is a deep purple and blue.

FDRS 2024

The Lipedema Research Roadmap: Recommendations and Resources

Jonathan Kartt
CEO, Lipedema Foundation



DISCLOSURES

Nothing to Disclose:

The Lipedema Foundation receives no external funding, and sells no products or services.

Disclaimer

This presentation is provided solely to educate consumers on medical issues that may affect their daily lives. Nothing should be considered, or used as a substitute for, medical advice, diagnosis or treatment. Always seek the advice of your qualified health provider with any questions you may have regarding a medical condition.



About the Foundation



Research Funding

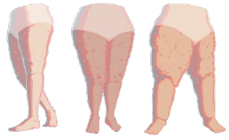
- 12.5M USD globally
- Understand biology, improve diagnosis

Infrastructure

- Lipedema Foundation Registry
- Biobanks and access to samples

Awareness

- General
- Patient
- Clinician



L I P E D E M A
F O U N D A T I O N



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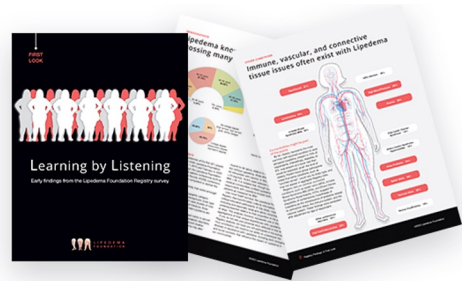


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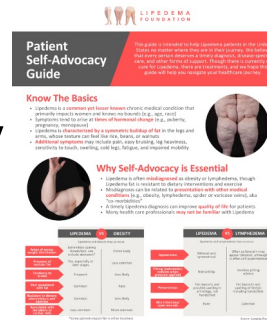


Resources – Lipedema.org

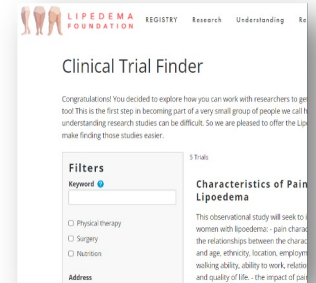
Patient Registry
[/registry](#)



Self Advocacy Guide
[/guide](#)



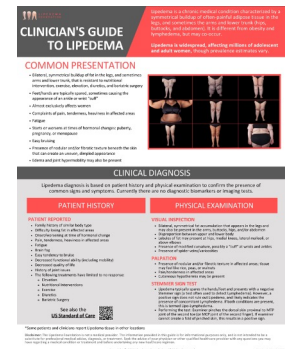
Clinical Trial Finder
[/legwork](#)



Brochure
[/brochure](#)



Clinician's Guide
[/clinicians-guide](#)



Plus Patient's Bill of Rights, LEGATO research library, patient stories, videos and CME...



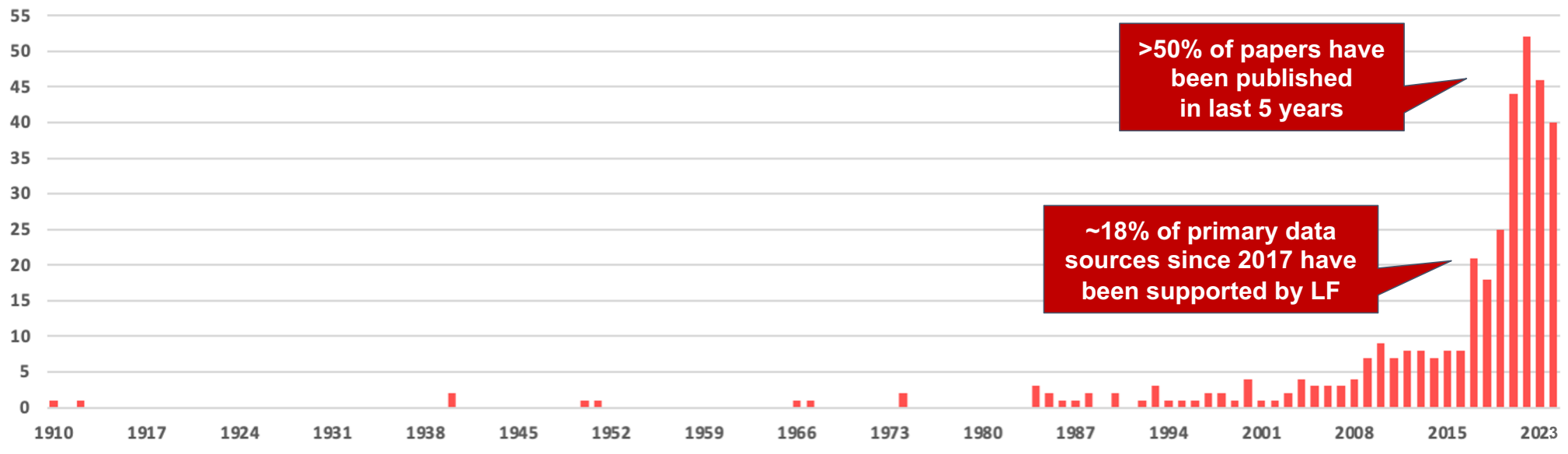
The Roadmap



A Renaissance in Lipedema Research?



Growth of Lipedema Primary Data Publications By Year



Primary data = collected from first-hand sources; excludes meta analyses, literature reviews, etc.
Source: LEGATO research library





Challenges and opportunities

- Poor understanding of the biology
- Reliance on clinical diagnosis
- Challenges to recruiting study participants
- Limited clinical and research workforce
- Limited research infrastructure

**Growing
clinical
awareness**

**Multiple NIH R01
grants to date
(Crescenzi,
Shawber)**

**Vanderbilt biobank
LF registry**



Lipedema Research Roadmap: Recommendations to advance research



- Biology
- Epidemiology
- Diagnosis & biomarkers
- Treatments
- Lexicon & best practices
- Environment & workforce

Lipedema.org/roadmap





Understanding the Biology Big questions – for example...



????????????

- Lower levels of metabolic disease despite increased adiposity?
- Why does it disproportionately impact the lower body - often sparing hands and feet?
- What explains unusual texture and palpable nodules many patients and clinicians report?
- What is the link between Lipedema and hypermobility?
- Do GLP-1 agonist drugs help - and what can that tell us about Lipedema biology?

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Source samples for research

What's needed

- Access to samples from well-diagnosed patients and controls
- Especially whole tissue

How can you help?

- Clinicians - let us know if you have samples to share
- Patients - watch out for future participation opportunities

Studies recruiting now & soon

Location	Study	Institution	Email	Phone
Baton Rouge, LA	Adipose Cellular Kinetics of Lipedema	Pennington Biomedical Research Center	ursula.white@pbrc.edu	225-763-2656
Laredo, TX	Impact of combination therapy on lipedema patient tissue stress	Cobos Endocrinology / Texas A&M	rutkowski@tamu.edu	
Nashville, TN	Visualizing Vascular Mechanisms of Lipedema (VMP)	Vanderbilt University Medical Center	salt@vumc.org	615-875-9935
Nashville, TN	Building Lipedema Research Resources (BRR)	Vanderbilt University Medical Center	caroline.crush@vumc.org	615-421-0243
Cleveland, OH	Vascular Lab Resource (VLR) Biorepository Study	The Cleveland Clinic	cameros3@ccf.org	216-444-1680



Recruit researchers and clinicians

What's needed

- Clinicians: OB/GYN, vascular, rheumatology, endocrinology, metabolic, dermatology, mental health, immunology...
- Researchers: Adipose, hormone, fascia, fibrosis...

How can you help?

- Become an evangelist in your discipline
- Interested in giving talks within your specialty?

Professional Societies: Awareness & Training

What's needed

- Talks on agendas
- Greater awareness among Society leaders and members

How can you help?

- Let us know if you're on boards, education committees, etc. of your societies
- Introductions to people who need to know about Lipedema

Research Idea Database

lipedema.org/ideadatabase



1 hidden field Filter Grouped by 1 field Sort ...

	Research Question, Hypothesis, or Idea	Subcategory All	Stakeholder Role	Nature of the observati...	Poten...
ROADMAP OBJECTIVE					
>	Objective 1: Research Environment, Workfor	Count 1			
ROADMAP OBJECTIVE					
∨	Objective 3: Diagnosis and Biomarkers	Count 2			
2	Investigate the use of millimeter wave technology (TSA scanners) to understand potential screening ...	Biomarkers – Morphom...	Person with Lip...	Patient Observation	Millim could
3	Is there a correlation between lipedema and Idiopathic Intracranial Hypertension (IIH)? Both ...	Comparator groups or s...	Person with Lip...	Patient Observation	Both under
ROADMAP OBJECTIVE					
∨	Objective 4: Characterize Biology	Count 5			
4	Individuals with Lipedema often report that their skin stops tanning and/or sunburning as Lipedema ...	Dermal	Person with Lip... Funder Other	Patient Observation	If this repre
5	Does the stagnancy of the lymph fluid in the body cause increased cholesterol? Does MI D help lower	Lymphatic	Person with Lip...	Patient Observation	Help their

14 records

Airtable Download CSV View larger version

Open database with option for privacy/ confidentiality





What do you think is important for researchers to study?

Research question, hypothesis, or idea *

Please describe the research idea, question, or hypothesis you would like to submit. Include enough detail to adequately describe your submission.

Responses are limited to 1,000 words.

Nature of the observation *

What generated the initial "spark" that led you to propose this idea?

- Patient Observation
- Clinician Observation
- Research Findings (Published)
- Research Findings (Unpublished)
- Research Findings (Conference/Other Presentation)
- Other
- Nature of the observation
- Patient Observation

Describe potential impact *

Describe the potential impact of this research idea/question. Why would answering this question advance our understanding of Lipedema diagnosis or treatment and/or lead to improved outcomes for people with

lipedema.org/ideadatabase



We want your ideas!





St. Louis

FDRS 2024

April 19-21



CONTACT INFORMATION

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Appendix





Lipedema Research Roadmap



- Engaged 60+ stakeholders, 11 countries
- 24 Reviewers – 1,300 suggestions

Lipedema.org/roadmap



Thank you again to our contributors, reviewers, and the LF team



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