

FDRS 2023 April 14-16



FAT DISORDERS
RESOURCE SOCIETY

Lipedema Research Roundup

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DISCLOSURES

Nothing to Disclose

The Lipedema Foundation receives no external funding, and sells no products, nor services.



Articles in this presentation that were funded by the Lipedema Foundation are noted by the Lipedema Foundation Logo



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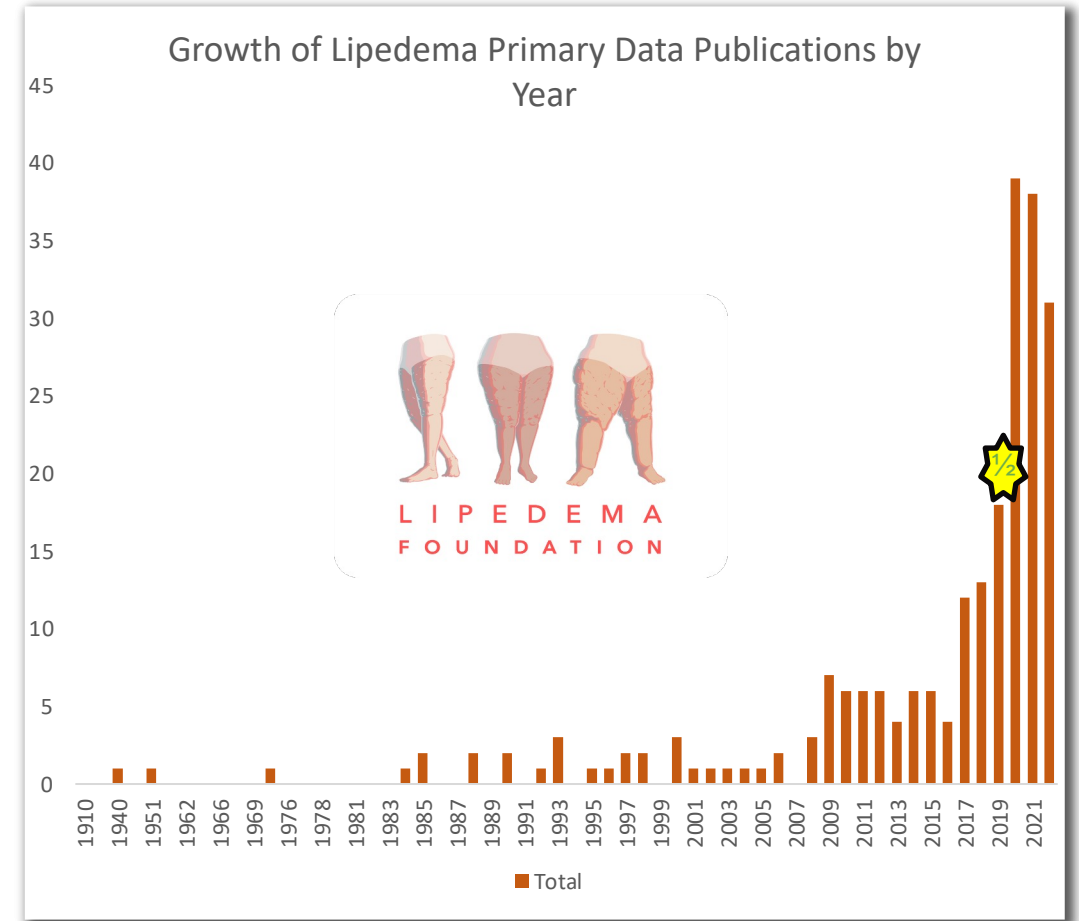
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Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.



General Direction of Field

- **Continued progress in discovery science and some advances on therapeutics**
- **Unpublished data challenge widely held beliefs**
- **Many barriers remain**
 - **Under-resourced environments**
 - **Too few investigators and too few granting mechanisms**
 - **It remains difficult to enroll substantial numbers of patients**
- **We need to ask more of research**



Guide to evaluating Research: Levels of Evidence

Strength	Level	Design	Randomization	Control
High	Level 1	Randomized control trial (RCT)	Yes	Yes
		Meta-analysis of RCT with homogeneous results	No	
	Level 2	Prospective comparative study (therapeutic)	No	Yes
		Meta-analysis of Level 2 studies or Level 1 studies with inconsistent results	No	
	Level 3	Retrospective Cohort Study	No	Yes
		Case-control Study	No	Yes
		Meta-analysis of Level 3 studies	No	
	Level 4	Case Series	No	No
Low	Level 5	Case Report	No	No
		Expert Opinion	No	No
		Personal Observation	No	No

Hydrocephalus Foundation

<https://www.hydroassoc.org/research-101-levels-of-evidence-in-hydrocephalus-clinical-research-studies/>

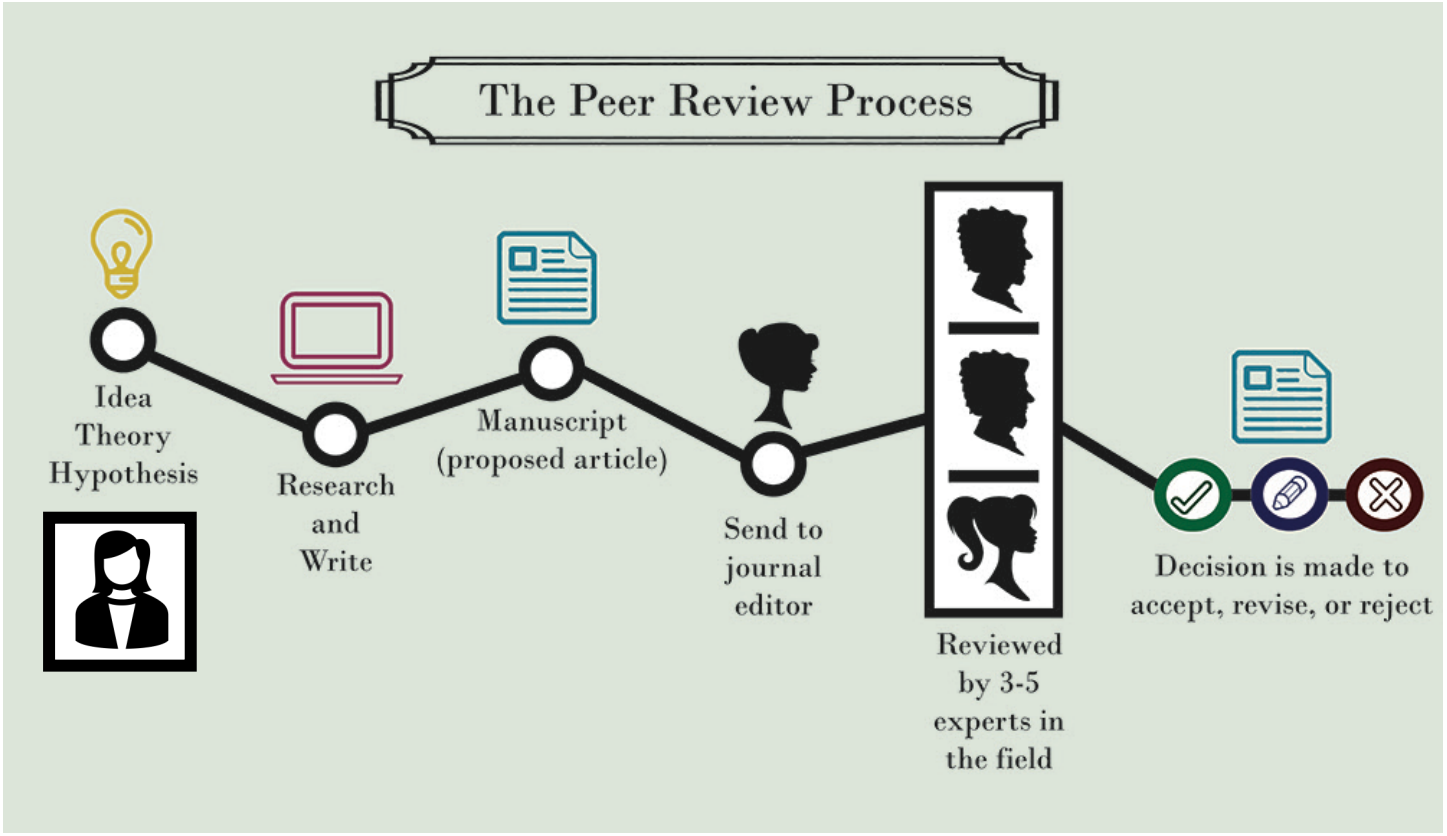


Guide to evaluating Research: Validity vs Legitimacy

Validity	Does the experiment address the question?
	Are the results statistically significant?
	Were the techniques applied correctly?
	Can the results be generalized?
Legitimacy	Are the conclusions consistent with the results?
	Were the biases of the author and funders taken into account?



Guide to evaluating Research: How peer review works and what it offers



University of California San Diego
<https://ucsd.libguides.com/mmw13/peerreview>



• Questions to ask

- Are they selling hope or just hype?
- The study says it’s about lipedema, but is it?
- Is the study discussing causation or correlation?
- Putting on your statistics hat
 - Is the study size right for the change they describe?
 - Do they have something to compare their findings to?
 - How did they select their study population?



Milestones and progress at the Lipedema Foundation

- Launched new research projects and a new RFP
- Launched two digital tools
 - Lipedema Library (Legato) and Clinical Trial Finder (Legwork)
- Published LF Registry first look with help from this community
 - 3000 enrolled, 700 completions!
 - LFR to support study recruitment
- Massive comparison of the diagnostic criteria used in Lipedema
- Back in person:
 - Relaunched LF research retreat
 - Recommitted to conference attendance and networking events
- Milestone reached: 175,000 brochures!



CRITERIA FOR LIPEDEMA DIAGNOSIS	1940	1981	1986	1991	2007	2017	2018	2018	2018	2021
HARD	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
ONSET	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
POPULATION AFFECTED	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
SYMPTOMS REQUIRED	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
FAMILY HISTORY	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
PAIN	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
DIAGNOSTIC TESTS	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
EXCLUSIONS	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA
TREATMENT	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA	LIPEDEMA



Advancing Research on Quality of Life

- The patient journey is diverse

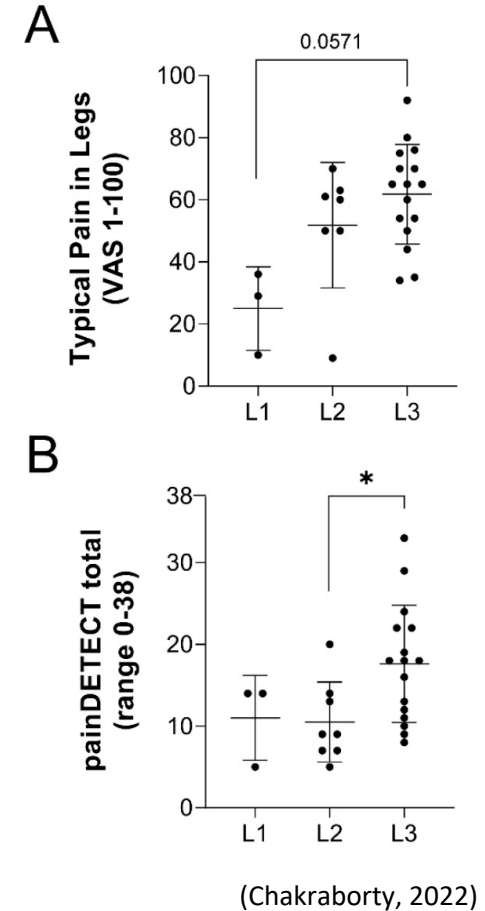


Patients report symptoms across the body – most researchers agree requires more rigorous study (Registry First Look, 2022)

- Socioeconomic and demographic factors like age may influence experiences (Falck, 2022) (SPEAKING TODAY!)
- Comorbidities may differ significantly between patients (Rockson, 2022)
- Quality of Life (QOL) is more than one number
 - Made of both quantifiable and abstract experiences
 - Stage doesn't capture all aspects of progression, but may still be a useful proxy (Clarke, 2022)
- Pain is an important facet of QOL
 - Nerve cell density may be reduced on abdomen (but not thigh)
 - Lipedema patients' thighs were more sensitive to specific pain stimuli



But not always in areas affected by Lipedema (Chakraborty, 2022) – so Lipedema may be exerting its effects at a distance



Discovery sciences

Entering the Genetics Era of Lipedema Research



Most studies report greater than half of patients have family history (Grigoriadis, 2022; Registry First Look, 2022)



First Genome Wide Association Study formally published (Grigoriadis, 2022)

- Suggested correlation of Lipedema to adipose and hormone related genes



Followup study replicated some initial findings + blood vessel related genes (Klimentidis, 2022)

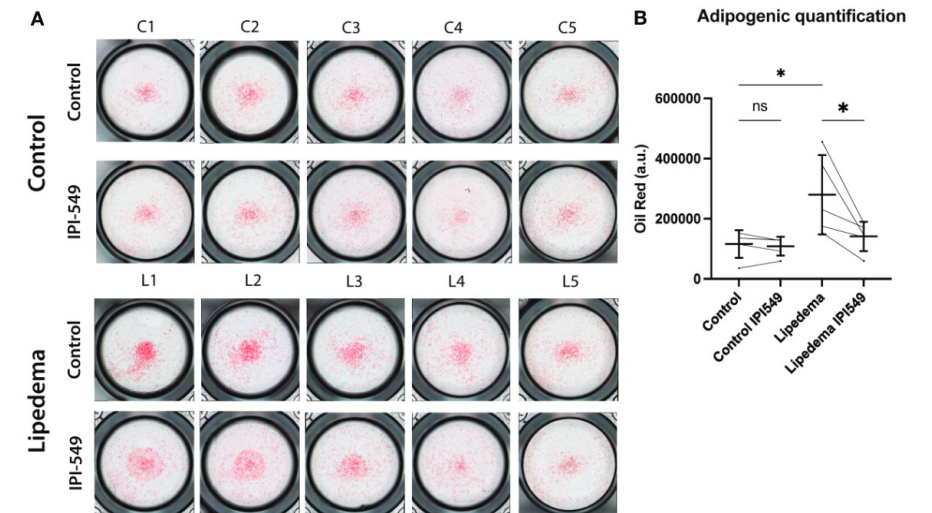
- Candidate gene approach published (Michelini, 2022)
- Are we ready for a genetic test ?

Other potential markers

- Are macrophages bystanders or participants in Lipedema?



Activated macrophages shown to change proliferation and differentiation of Adipose Stem Cells (Wolf, 2022)



(Wolf, 2022)



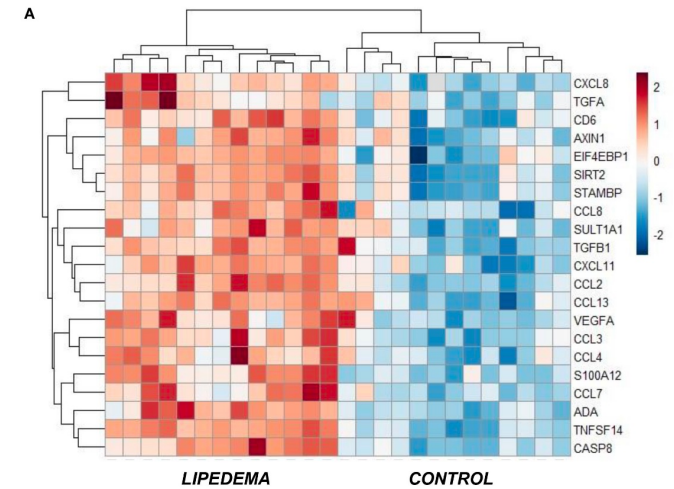
Nutrition and Metabolism

- **Nutrition**

- Multiple supplement hypotheses published

- **Metabolism**

- **Lipedema is generally NOT associated with metabolic disorders (Torre, 2018)**
- **New report (Nankam, 2022)**
 - **Better glucose metabolism than controls**
 - **But higher total cholesterol, LDL**
 - **Higher SYSTEMIC inflammation**



(Nankam, 2022)



Progress in Imaging Lipedema

- **DEXA (Dual x-ray absorptiometry)**

- Simple, common technique reporting 95% sensitivity, 73% specificity (Buso, 2022)
- Measures leg to total fat mass, results independent of stage

- **Lymphangiography**

- Most studies to date suggest some edema (even if clinically insignificant)
- 3 studies in 2022 suggest nuance to how lymphatics may be perturbed



Differences in Lipedema edema pattern vs Lymphedema (Crescenzi, 2022)

- Transport differences ( Rasmussen, 2022; Zaleska, 2022)



Progress in Evaluating Therapies

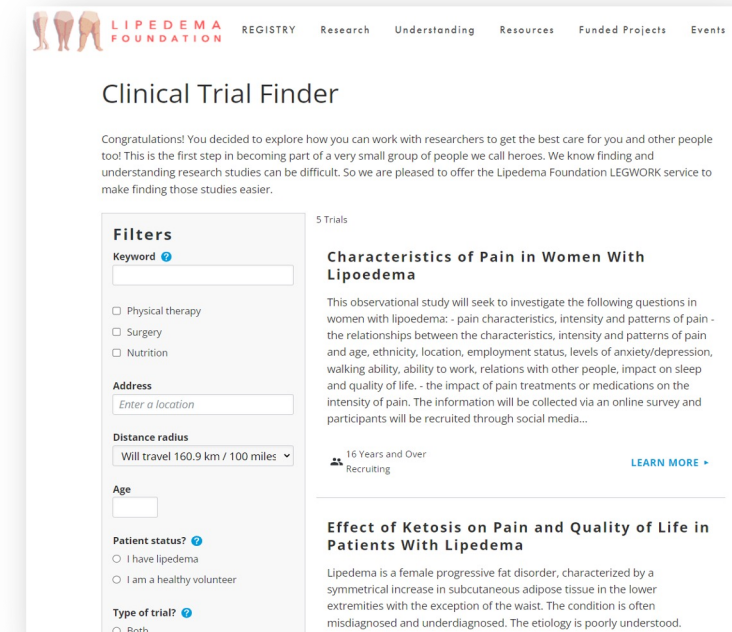
- **Garments and machine-assisted compression largely upheld as effective**
 - QOL, and body composition (?) advantages
 - Pain and volume changes may require larger studies to detect
- **Surprising changes suggested!**
 - Skin thickness?
 - Tissue Sodium?
 - Skin temperature?

(Czerwinska, 2023; Wright, 2022; Sanchez-Jimenez, 2023)



What's coming and how to learn more

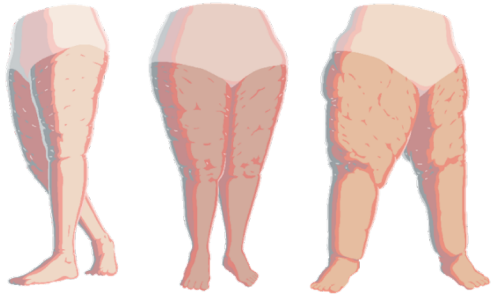
- Lipedema Research Roadmap
- Get Connected in Research
 - LF blogs
 - Legwork
 - Legato
- Join the Lipedema Foundation Registry
- Evaluating science resources
- References for this talk at
 - lipedema.org/blog
 - The Power of a Pivotal Year in Lipedema Research



The screenshot shows the 'Clinical Trial Finder' page on the Lipedema Foundation website. The page features a navigation bar with links for 'REGISTRY', 'Research', 'Understanding', 'Resources', 'Funded Projects', and 'Events'. Below the navigation bar, there is a 'Clinical Trial Finder' section with a congratulatory message and a 'Filters' sidebar. The filters include 'Keyword', 'Address', 'Distance radius', 'Age', 'Patient status?' (with options for 'I have lipedema' and 'I am a healthy volunteer'), and 'Type of trial?' (with options for 'Both'). The main content area displays a trial titled 'Characteristics of Pain in Women With Lipedema' with a brief description and a 'LEARN MORE' link. Below this, another trial titled 'Effect of Ketosis on Pain and Quality of Life in Patients With Lipedema' is partially visible.

Searchable database of actively enrolling studies
www.lipedema.org/legwork





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www.fatdisorders.org/events