

Lipedema Research

Progress Amidst Pandemic



Jonathan Kartt
Chief Executive Officer

Guy Eakin, PhD
Chief Science Officer



Disclosures

Nothing to Disclose

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



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Nothing in the Content should be considered, or used as a substitute for, medical advice, diagnosis or treatment.

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





Lipedema Foundation – New Faces



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Founder



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Guy Eakin, PhD
Chief Science Officer



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Find Lipedema Research Literature

LEGATO Comprehensive Lipedema Research Library



Lipedema Foundation LEGATO library

An orderly approach to a complex disorder

THE LEGATO LIBRARY

Lipedema is complex. Finding Lipedema research should never be. The Legato library is a comprehensive and up-to-date archive of research publications specifically related to Lipedema.

Lipedema research is scarce and sometimes difficult to locate even with modern internet tools. The Legato library organizes scholarly works, functioning as digital research infrastructure. By doing so, we make the data behind today and tomorrow's care more accessible to the women with Lipedema and the research community that serves them.



SEARCH THE LIBRARY

Beta Launch
Curated and full-text searchable publications
www.lipedema.org/library



Lipedema Foundation LEGATO Lipedema Library Bibliography

Explore

Topic

- Genetics (12)
- Guidelines and Consensus (35)
- LF Funded (45)
- Lipedema (501)
- Open Access (142)
- Original studies and data (189)
- Personal management (diet, exercise, nutrition) (7)
- Review (252)
- Therapeutics (61)

Resource type

- Book (10)
- Book Section (26)
- Conference Paper (7)
- Document (5)
- Journal Article (515)
- Magazine Article (4)
- Newspaper Article (1)
- Patent (1)
- Preprint (2)
- Report (13)
- Thesis (3)
- Web Page (6)

Search

Q

? Help

Full bibliography 593 resources Sort by: Oldest first ▼

1

2

3

4

5

...

30

▶

🔗 Abstracts

LYON, I. P. (1910). ADIPOSIS AND LIPOMATOSIS: CONSIDERED IN REFERENCE TO THEIR CONSTITUTIONAL RELATIONS AND SYMPTOMATOLOGY. *Archives of Internal Medicine*, VI(1), 28–120.
<https://doi.org/10.1001/archinte.1910.00050290033005>
[View on doi.org](#)

Allen, E., & Hines, E. (1940). Lipedema of the legs: a syndrome characterized by fat legs and orthostatic edema. *Proc Staff Meet Mayo Clin*, 15, 184–187.

Moncorps, C., Brinkhaus, G., Herteld, F., & others. (1940). Experimentelle untersuchungen zur frage akrozyanotischer zustandsbilder. *Arch Derm Syph*, 186, 209–215.

CASANUEVA del CAMPO, M. (1950). [Allen Hines' syndrome; lipo-edema of the legs (obesity of lower extremities and orthostatic edema)]. *Revista medica de Chile*, 78(12), 804–806.





Get Involved in Research – LEGWORK Clinical Study Finder



Lipedema Foundation LEGWORK

Clinical Study Finder - Engaging in Research. Partnering for Progress.

BECOME A PART OF DISCOVERY

Congratulations! You decided to explore how you can work with researchers to get the best care for you and other people too! This is the first step in becoming part of a very small group of people we call heroes. We know finding and understanding research studies can be difficult. So we are pleased to offer the Lipedema Foundation LEGWORK service to make finding those studies easier.

FINDING A STUDY IN THE US OR AROUND THE WORLD

LEGWORK is designed to help people with Lipedema and related conditions find studies to support their own care and the advance the care of others. Use LEGWORK to:

- Access simple search filters that quickly search several clinical research databases.
- Click through the results to learn more about each study.
- Discuss specific candidate studies with your healthcare provider by sharing the study URL with your care team.
- Get in direct contact with the study's coordinator.



[FIND A STUDY NOW](#)

Searchable database of actively enrolling studies

www.lipedema.org/legwork



LIPEDEMA FOUNDATION

REGISTRY

Research

Understanding

Resources

Funded Projects

Events

Clinical Trial Finder

Congratulations! You decided to explore how you can work with researchers to get the best care for you and other people too! This is the first step in becoming part of a very small group of people we call heroes. We know finding and understanding research studies can be difficult. So we are pleased to offer the Lipedema Foundation LEGWORK service to make finding those studies easier.

Filters

Keyword ?

Physical therapy

Surgery

Nutrition

Address

Distance radius

Age

Patient status? ?

I have lipedema

I am a healthy volunteer

Type of trial? ?

Both

5 Trials

Characteristics of Pain in Women With Lipedema

This observational study will seek to investigate the following questions in women with lipoedema: - pain characteristics, intensity and patterns of pain - the relationships between the characteristics, intensity and patterns of pain and age, ethnicity, location, employment status, levels of anxiety/depression, walking ability, ability to work, relations with other people, impact on sleep and quality of life. - the impact of pain treatments or medications on the intensity of pain. The information will be collected via an online survey and participants will be recruited through social media...

16 Years and Over
Recruiting

[LEARN MORE >](#)

Effect of Ketosis on Pain and Quality of Life in Patients With Lipedema

Lipedema is a female progressive fat disorder, characterized by a symmetrical increase in subcutaneous adipose tissue in the lower extremities with the exception of the waist. The condition is often misdiagnosed and underdiagnosed. The etiology is poorly understood.



Lipedema Foundation 2021 Awards

Lipedema Foundation
2021 Research Awards

Philipp Kruppa, MD
Alexander Huppertz, MD, PhD
Mojtaba Ghods, MD, PhD

Klinikum Ernst von Bergmann gGmbH
Department of Plastic, Aesthetic and
Reconstructive Microsurgery/Hand Surgery
Potsdam, Germany

Project: Morphological MRI Investigation of
Subcutaneous Adipose Tissue in Lipedema Patients



Lipedema Foundation
2021 Research Awards

Alan Pittman, PhD
Pia Ostergaard, PhD
Kristiana Gordon, PhD

St. George's, University of London
Molecular and Clinical Sciences
London, UK

Project: Deciphering the Genetic Basis of Lipedema



Lipedema Foundation
2021 Research Awards

Scott J. Cameron, MD, PhD

Cleveland Clinic Foundation

Project: Platelets as Biosensors
and Regulators of
Metabolism in Lipedema





Lipedema Foundation
2021 Research Awards

Susanne Wolbank, PhD
Eleni Priglinger, PhD

Ludwig Boltzmann Institute for Traumatology

Project: EV-miRNAs as Diagnostic Biomarkers
for Lipedema



Lipedema Foundation
2021 Research Awards

Bruce Alan Bunnell, PhD

University of North Texas Health Center
Fort Worth, TX

Project: Estrogen Signaling in Adipose Tissue
Metabolism and Development of Lipedema



Lipedema Foundation
2021 Research Awards

Brant Isakson, PhD

University of Virginia School of Medicine
Fort Worth, TX
Charlottesville, VA

Project: Project: Dysfunctional Gap Junction Communication
Between Endothelium and Adipocytes in Lipedema



Lipedema Foundation
2021 Research Awards

Manuel Cornely, MD, PhD
Ly.Search GmbH, Cologne, Germany

Oliver A. Cornely, MD, PhD
University of Cologne, Cologne, Germany

Till Hasenberg, MD, PhD
Helios Medical Center, Niederberg, Germany

Project: How Does Obesity Therapy Affect Lipedema?



Lipedema Foundation
2021 Research Awards

Eric Ravussin, PhD
Ursula White, PhD

Pennington Biomedical Research Center
Clinical Science
Baton Rouge, LA

Project: A Novel Approach to Examine
Adipose Cellular Kinetics of Lipedema





Lipedema Foundation
2021 Research Awards

Joseph Rutkowski, PhD
Dr. Leopoldo Cobos-Salinas, MD

Texas A&M University College of Medicine
Medical Physiology
Bryan, TX

Project: Impact of Combination Therapy on
Lipedema Patient Tissue Stress



Lipedema Foundation
2021 Research Awards

Samuel Klein, MD
Vincenza Cifarelli, PhD

Washington University School of Medicine
Center for Human Nutrition
St. Louis, MO

Project: Adipose Tissue Biology and Effect
of Weight Loss in Women with Lipedema



Lipedema Foundation
2021 Research Awards

Atefeh Rabiee, PhD

University of the Pacific

Project: Turning up the Heat
on Lipedema



Lipedema Foundation
2021 Research Awards

Evangelia Bellas, PhD
Temple University

Jennifer Munson, PhD
Fralin Biomedical Research Institute at VTC

Project: Characterization of Biotransport
through Engineered Lipedemic Tissues



Lipedema Foundation
2021 Research Awards

René Hägerling, MD, PhD

Charité - Universitätsmedizin Berlin
Institute of Medical and Human Genetics
Berlin, Germany

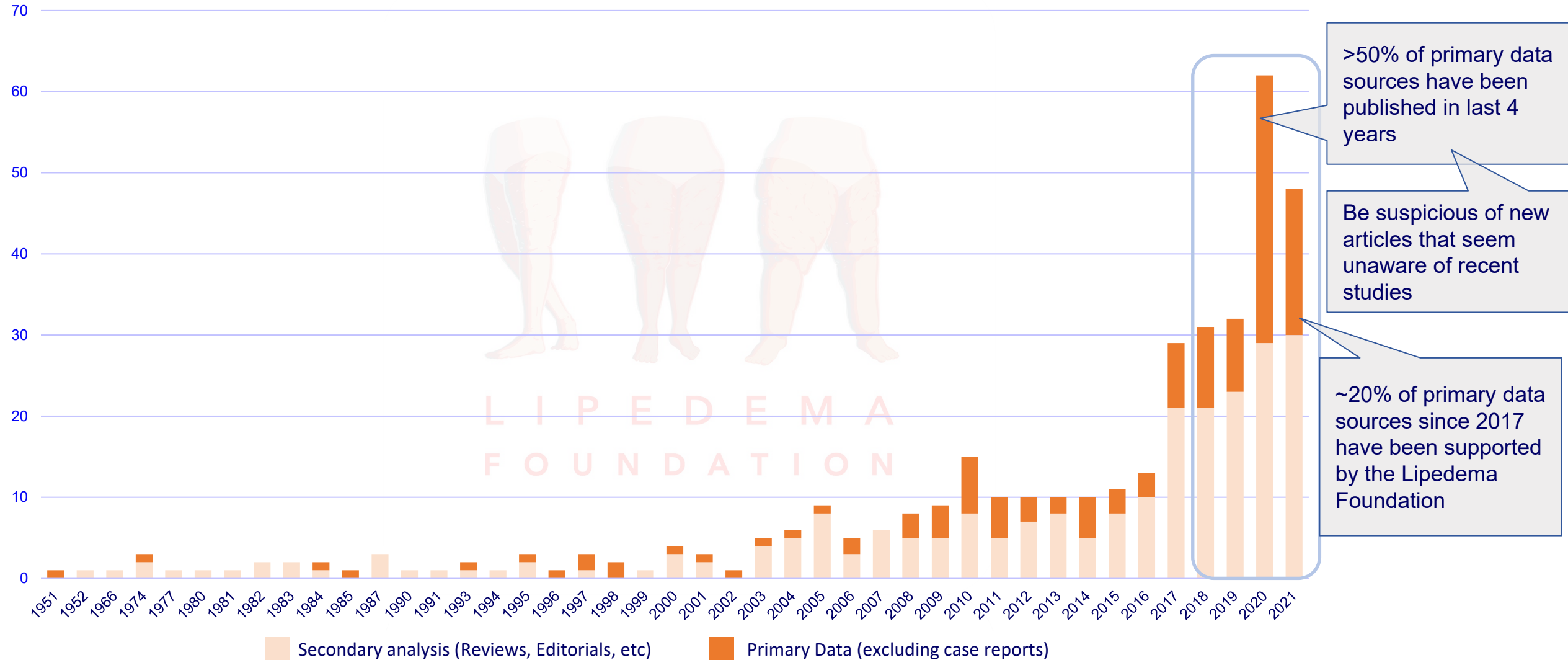
Project: 3D-Histopathology of Lipedema





Lipedema Research Landscape is Expanding

Approximately 1/3rd of Journal Articles Published on Lipedema Present Primary Data





NIH Gave its 1st Research Grant

NIH RePORT RePORTER FAQs API ExPORTER (Beta) Sign In

Search Results 2 Projects Save... Export Share

lipedema Search

Projects Publications Patents Clinical Studies News & More Results are sorted by Relevance

T	Act Project	Year	Sub	Principal Investigator(s)/ Project Leader(s)	Organization	Fiscal Year	Admin IC	Funding IC	FY Total Cost by IC	Similar Projects
	Visualizing vascular mechanisms of lipedema									
1	R01HL157378-01			CRESCENZI, RACHELLE L	VANDERBILT UNIVERSITY MEDICAL CENTER	2021	NHLBI	NHLBI	\$508,350	View
	Standard of Care for Lipedema in the United States									
1	R13HL147503-01			HERBST, KAREN LOUISE	UNIVERSITY OF ARIZONA	2019	NHLBI	NHLBI	\$3,006	View

Filters: Active Projects [Fiscal Years](#) [Org Names](#)



Dr. Rachelle Crescenzi
Vanderbilt University
Medical Center





The US Standard of Care

Strengths:

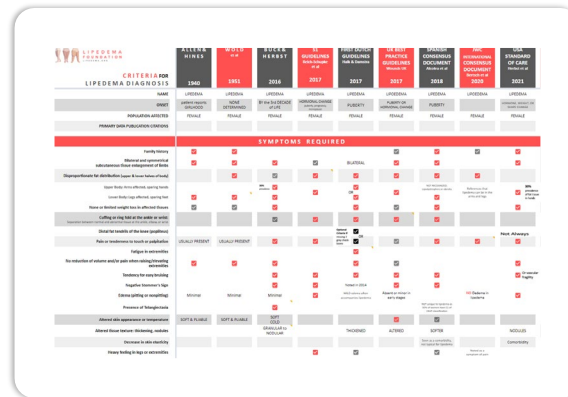
- **Delphi** - Developed with a “voting” approach to prevent one opinion from dominating discussion
- **Broad scope** – Documents consensus of authors on Diagnosis, Therapeutic approach AND some non-medical aspects

Wait and Sees

- **Evidence Grading** - is challenging in Lipedema. As data emerge, the SOC will require periodic review

- **Differences from other professional points of view**



Stop by the Lipedema Foundation booth for a breakout of how guidelines compare.





Phlebology

Original Article

Standard of care for lipedema in the United States

Karen L Herbst^{1,2,3} , Linda Anne Kahn^{2,4}, Emily Iker^{2,5}, Chuck Ehrlich^{2,6}, Thomas Wright^{2,7} , Lindy McHutchison^{2,8}, Jaime Schwartz^{2,3}, Molly Sleigh^{2,9}, Paula MC Donahue^{2,10}, Kathleen H Lisson^{2,11}, Tami Faris^{2,12}, Janis Miller^{2,13}, Erik Lontok^{2,14}, Michael S Schwartz^{2,15}, Steven M Dean^{2,16}, John R Bartholomew^{2,17}, Polly Armour^{2,18}, Margarita Correa-Perez^{2,19}, Nicholas Pennings^{2,20}, Edely L Wallace^{2,21} and Ethan Larson^{2,22}

Phlebology
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DOI: 10.1177/02683555211015887
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Abstract

Background: Lipedema is a loose connective tissue disease predominantly in women identified by increased nodular and fibrotic adipose tissue on the buttocks, hips and limbs that develops at times of hormone, weight and shape change including puberty, pregnancy, and menopause. Lipedema tissue may be very painful and can severely impair mobility. Non-lipedema obesity, lymphedema, venous disease, and hypermobile joints are comorbidities. Lipedema tissue is difficult to reduce by diet, exercise, or bariatric surgery.

Methods: This paper is a consensus guideline on lipedema written by a US committee following the Delphi Method. Consensus statements are rated for strength using the GRADE system.

Results: Eighty-five consensus statements outline lipedema pathophysiology, and medical, surgical, vascular, and other therapeutic recommendations. Future research topics are suggested.

Conclusion: These guidelines improve the understanding of the loose connective tissue disease, lipedema, to advance our understanding towards early diagnosis, treatments, and ultimately a cure for affected individuals.



Some things haven't changed

General Cautions About Lipedema Research

- Small Field
 - Be excited, but stay skeptical
 - Most science requires repetition
- Under-funded field
 - Studies are small and often lack necessary controls
 - Combining stages is often necessary
 - Tendency for imprecise measurements
 - Double blinding often isn't possible
 - Be skeptical of unblinded Pain or Quality of Life measurement



New Nutrition Data Including first Lipedema Data on Keto

The Background:

- Nutrition is one of the few things you change yourself
- Very little medical literature specific to Lipedema

The Studies

- Apkhanova (2021) -- Ketogenic Diet and Nutraceutical Correction
- Di Renzo, L. (2021) -- Modified Mediterranean Diet on Body Composition Nutrients.
- Sørli, V. (2021) Effect of a ketogenic diet on pain and quality of life.

Cautions

- These are “modified” and personalized plans
- Sometimes benefits are not specific to lipedema symptoms

General conclusions

- Numbers supports belief that weight loss is possible, but disproportionate
- If helpful for pain, maybe only when actively on the program
- There may be many successful dietary approaches for any person

More details at

1. Our Booth
2. lipedema.org/fdrs-2022

2021 Nutrition Research Publications

Citation	Approach	Cautions	Main finding
Apkhanova, T.V. et al. (2021) [Influence of Ketogenic Diet and Nutraceutical Correction in the Complex Treatment of Lower Limbs Lipedema.] Bulletin of Restorative Medicine 20, 26–36	60 patient randomized study (4wks) Arm 1) Low Calorie (1300 C) diet + Exercise Arm 2) modified Atkins + Exercise + nutraceutical (appetite suppressant + 'hepatoprotection')	Very little information on the nutraceutical Small study by diet study standards No non-lipedema controls Specific lipedema features not measured	↓ Weight in both groups ↑ Leptin
Di Renzo, L. et al. (2021) Potential Effects of a Modified Mediterranean Diet on Body Composition in Lipedema. Nutrients 13,	14 Lip pts (Stage 1-4), 15 Controls Modified Mediterranean Diet (20% reduction in calories, anti-inflammatory/antioxidant diet)	Small study, combined all stages Intervention time was "period of greatest adherence to prescribed diet"	All groups ↓ weight and BMI ↔ between ctrl and lip at 4 wks except CTRL lost more truncal fat mass CTRL had more success in ↓ intramuscular adipose. ↔ Pain in Lip ↑ QOL in Lip pts than in CTRL
Sørli, V. et al. (2021) Effect of a ketogenic diet on pain and quality of life in patients with lipedema: The LIPODIET pilot study. Obesity Science & Practice	Measured patients to themselves during 7 wks ON low calorie dietician guided LIPODIET diet and 6wks on Nordic Nutrition standards (no calorie reduction)	Very small study – 9 people Needs other controls to address cause and effect	↑ Waist, hip, calf circumference ↔ Thigh circumference ↑ Pain when diet ceased Authors argue general low carb diet may have better success (eg Mediterranean)





Conservative Therapy Shows Benefits

The Background:

- The value of conservative therapy has been challenged by some medical opinions and insurer policies

The Studies

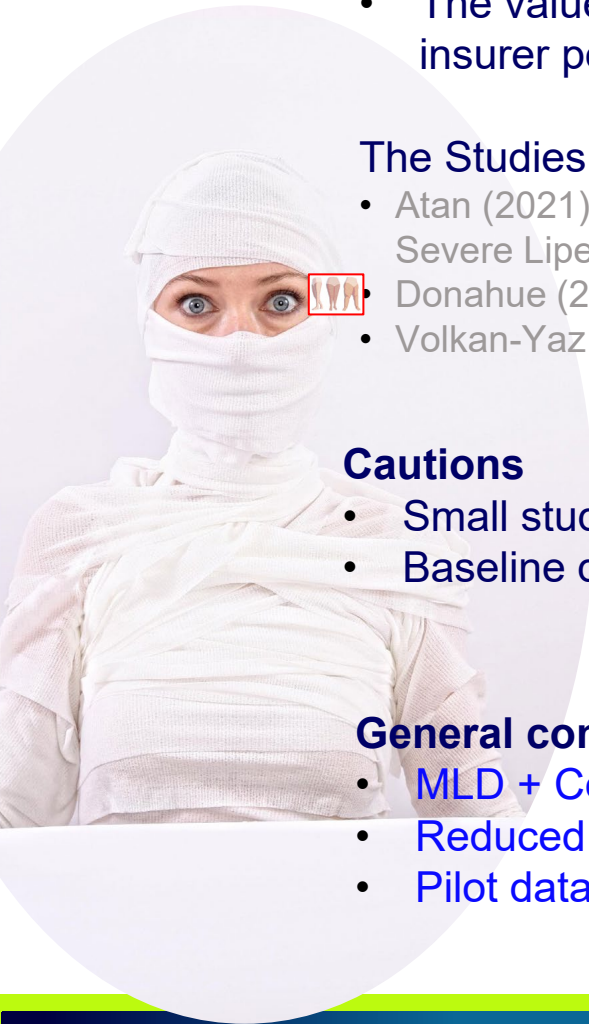
- Atan (2021) -- RCT. Effects of Complete Decongestive Therapy or Intermittent Pneumatic Compression on Severe Lipedema: [A Randomized Controlled Trial.](#)
- Donahue (2021) Physical Therapy in Women with Early Stage Lipedema
- Volkan-Yazıcı (2021) Complex Decongestive Physiotherapy in Patients with Lipedema

Cautions

- Small studies - but show possibility of statistical power for some measures
- Baseline demographics sometimes different between populations

General conclusions

- MLD + Compression shows benefits in late stages (no extra benefit to IPC)
- Reduced limb volume, pain and physical function
- Pilot data in Stage 1-2, suggest benefit and possible changes in molecular markers of inflammation





Surgery Studies Move Beyond the Operating Room

The Big Picture:

- Largest growing area of Lipedema data (still, <10 studies)
- Focused on operative outcomes (e.g., volume of lipoaspirate, leg volume reduction)
- -- emerging attention to other patient priorities

The Studies

- Cornely (2022) *Lipedema Pain after Bariatric Surgery*
- Herbst (2021). Survey Outcomes of Lipedema Reduction Surgery in the United States.
- Kruppa, (2022). *10 year outcomes of Lipedema Surgery survey*
- Sandhofer, (2021). *Safety of high volume liposuction*
- Schlosshauer, (2021) *Liposuction treatment improves disease-specific quality of life in lipoedema patients*

Cautions

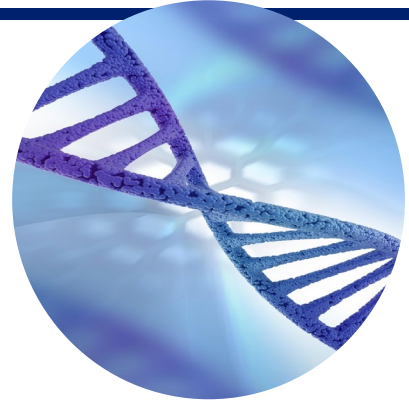
- QOL measures have not been validated in Lipedema patients.

General conclusions

- Liposuction generally reduces need for conservative therapy and pain in all stages
- – there may be benefit to earlier stage or age intervention
- Significant adverse events are rare.
- -- Less severe events (fibrosis, anemia) may occur more frequently
- Continued growth of lipedema affected tissue is possible even after surgery.
- Bariatric surgeries may support weight loss, but may be less likely to reduce lipedema symptoms



New Genetics Studies Focus Attention on Unique Causes of Lipedema



The Big Picture:

- Family history of Lipedema is 30-89% in recent research
- Genetics research has failed to identify strong contributors to risk of Lipedema
- Genetics is very helpful for understanding origins of a disease

The Studies

- Michelini (2022) A Multi-Gene Panel of genetic variants. Journal of Personalized Medicine
- Ishaq (2021) Key signaling networks are dysregulated in patients with the adipose tissue disorder, lipedema



Grigoriadis, D (2021) Genetics of 'UK Lipoedema' cohort.

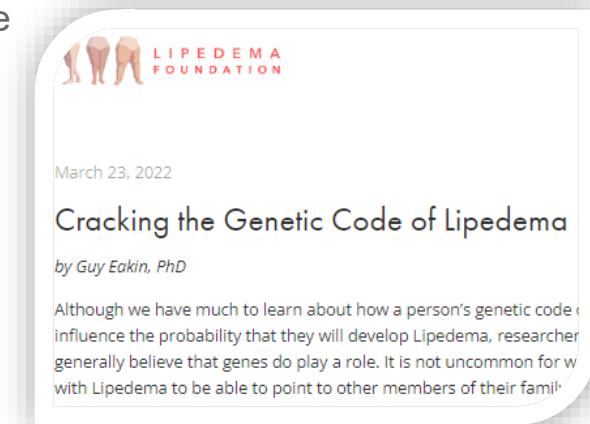
Cautions

- Control groups especially hard to define.
- Statistical association of genes does not mean the gene causes Lipedema
- Most genetics research needs thousands of participants

General conclusions

- Highlighting molecules involved in regulation of adipose, estrogen, and cell division.
- Genetic testing based on current knowledge is statistically unlikely to offer insight into risk for Lipedema beyond a family history

Recent LF Blog



lipedema.org/blog









Other areas with new questions



The Role of Sex Hormones

-  Katzer, K. et al. (2021) Lipedema and the Potential Role of Estrogen in Excessive Adipose Tissue Accumulation
-  Al-Ghadban, S. et al. (2021) Estrogen as a Contributing Factor to the Development of Lipedema.

New Models of Lipedema

-  Stanley, T.L. et al. (2021) Growth, body composition, and endocrine issues in Williams syndrome.
-  Muley, A. et al. (2021) Unique functions for Notch4 in murine embryonic lymphangiogenesis.

Epidemiology

- Herpertz, U. (2021) The Prevalence Was Probably Overestimated (Comment on Kruppa 2020).



What do we need to fix?

Access to Patients

- Better tools to support the clinical diagnosis
- Larger studies
- Diverse

Better understanding of what goes wrong in Lipedema

- How does Lipedema develop?
- How does vary between people?

Measure and Move the Field.

- How do we turn those learnings into:
- New ways to treat lipedema
- Strong and reproducible measurements



What do we need to fix?

Acceptance that the status quo is good enough

skin" in appearance. This usual picture is so differentiated and obvious that the clinical diagnosis is no problem.

1974 paper

How can you be involved?

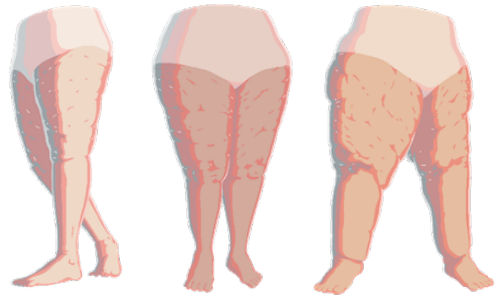


Getting involved in research can be as easy as picking up your phone

- COVID related perceptions and beliefs of the FDRS community
- How have you fared? How do you think about COVID?
- Go to:
 - lipedema.org/survey
 - scan the QR code
 - See our booth
- Results at tomorrow's registry talk



CONTACT INFORMATION



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



Visit our Booth!

Reach any of our staff by email
info@lipedema.org

Or connect via social media.

Notes, references, and more at lipedema.org/fdrs-2022



FAT DISORDERS
RESOURCE SOCIETY

FDRS 2022
April 22-24
Intercontinental Hotel Cleveland (at Cleveland Clinic)
Cleveland, OH



Patient Reported Outcomes



The Big Picture:

- Patient reported data can be very informative
- Standardized questions can accurately measure complex symptoms (pain, QOL, etc)
- Many clinical trials now also focus on these measures

The Studies

- Angst (2021) – Comparison of Fibromyalgia and Lipedema.
- Dudek (2021) - Quality of life study of Polish women with lipedema
- Lipedema Foundation Registry First Look – FDRS 2022 Talk

Cautions

- Still no validated measures for a Lipedema Population
- Lipedema symptoms can be complex, and difficult to measure completely

General conclusions

- Measurements of one QOL factor may help predict other QOL indicators
- Some patient reported measures are showing early signs of being able to support differential diagnosis