

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. The city lights are visible in the background, and the lights from the buildings and the arch are reflected in the water in the foreground.

# FDRS 2024

## *Lipedema Research: Current Status and Future Perspectives*

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CSO, Lipedema Foundation



**FAT DISORDERS**  
RESOURCE SOCIETY

# DISCLOSURES

## **Nothing to Disclose:**

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

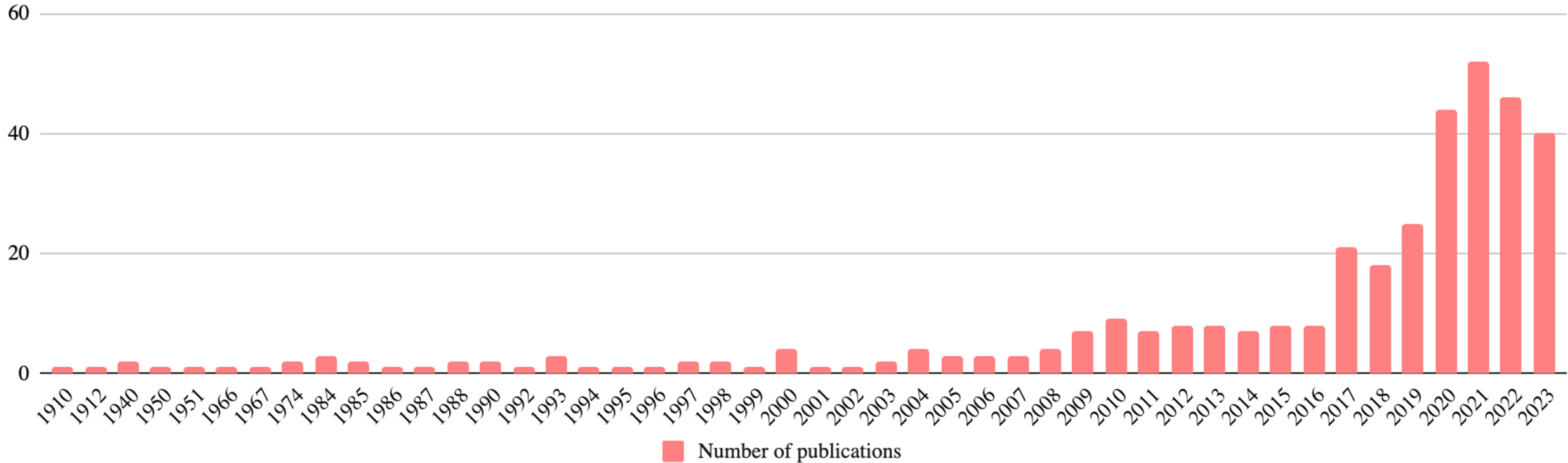
## **Disclaimer**

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.



# A Growing Field - Lipedema Publications

Number of Primary Data Publications Per Year



<https://www.lipedema.org/blog/2024/1/24/2023-research-roundup>





# Carrie Shawber - NIH R01 Grant



Second grant to an LF investigator

Shawber Lab: Columbia University  
Irving Medical Center

Notch pathway in adult vasculature

Investigating a potential link between  
Notch signaling defects and  
Lipedema

LF provided early funding support for  
this effort



# Research Update 2023

## Understanding Symptoms

Lipedema patients often report symptoms outside the lower body, suggesting *systemic* consequences beyond visibly affected areas.

This study is one of the largest Lipedema symptomatology survey cohort reported to date in the United States. (n=707 Lipedema, n=216 controls)

It is foundational, allowing comparison of symptoms in cohorts from other countries to establish the range of variation and to evaluate therapy outcomes

(Aday, et al. DOI: [10.1177/1358863X231202769](https://doi.org/10.1177/1358863X231202769))



# Research Update 2023

Lipedema pain is real and physical, not just “in the mind”

Pain perception is different in Lipedema and non-Lipedema individuals

13 different pain measures were evaluated

Two were highly informative for Lipedema - PPT and VDT

Combining **P**ressure **P**ain **T**hreshold (PPT) and **V**ibration **D**etection **T**hreshold (VDT) of **thigh versus hand** into a PVTH-score correctly categorizes 96.5% of the participants as Lipedema patients or healthy controls.

May become useful for diagnostics in the future

(Dinnendahl, et al. DOI: <https://doi.org/10.1101/2023.04.25.23289086>)



# Research Update 2023

## Nutrition

Low Carb High Fat (LCHF) diet holds promise for weight loss, body fat reduction, leg volume management, and pain alleviation in women with Lipedema. **(n=56 Lipedema, n=57 Ob, no Lipedema)**

(Malgorzata, et al. DOI: 10.1155/2023/5826630)

Modified Mediterranean-Ketogenic Diet and Carboxytherapy

Note: carboxytherapy is not FDA approved **(Small n=22 total)**

(Di Renzo, et al. DOI:10.3390/nu15163654)



# Research Update 2023

## Conservative Therapy

Compression therapy, combined with exercises, could improve the quality of life and decrease the severity of Lipedema symptoms (**n = 6**)

(Czerwińska, et al., DOI: [10.3390/ijerph20020914](https://doi.org/10.3390/ijerph20020914))

Complex decongestive therapy (CDT) and pneumatic compression improved extremity volume and circumference (**n = 15**).

(Murat, et al., DOI: [10.1089/lrb.2023.0013](https://doi.org/10.1089/lrb.2023.0013))





# Research Update 2023

## Liposuction outcomes

A meta-analysis of seven studies reports significant symptomatic relief post-op. Patients reported improvements in spontaneous pain, edema, bruising, mobility, and quality of life among Lipedema patients undergoing liposuction. Over 50% of the patients needed conservative therapy after surgery. ([Amato, et al. DOI:10.7759/cureus.55260](#))

Improvements in pain, mobility, and psychological variables in Lipedema patients age 18-35 ([Arndt, et al. Med Discoveries. 2024; 3\(2\): 1126](#))

LRS led to improvements in pain, knee flexion, gait, QoL measures (**n = 189 total, LRS = 66**)

([Wright, et al. DOI: 10.1097/GOX.00000000000005436](#))

Liposuction reduced pain post-op (**n=869**) ([Seefeldt, et al. DOI: 10.1111/ddg.15064](#))

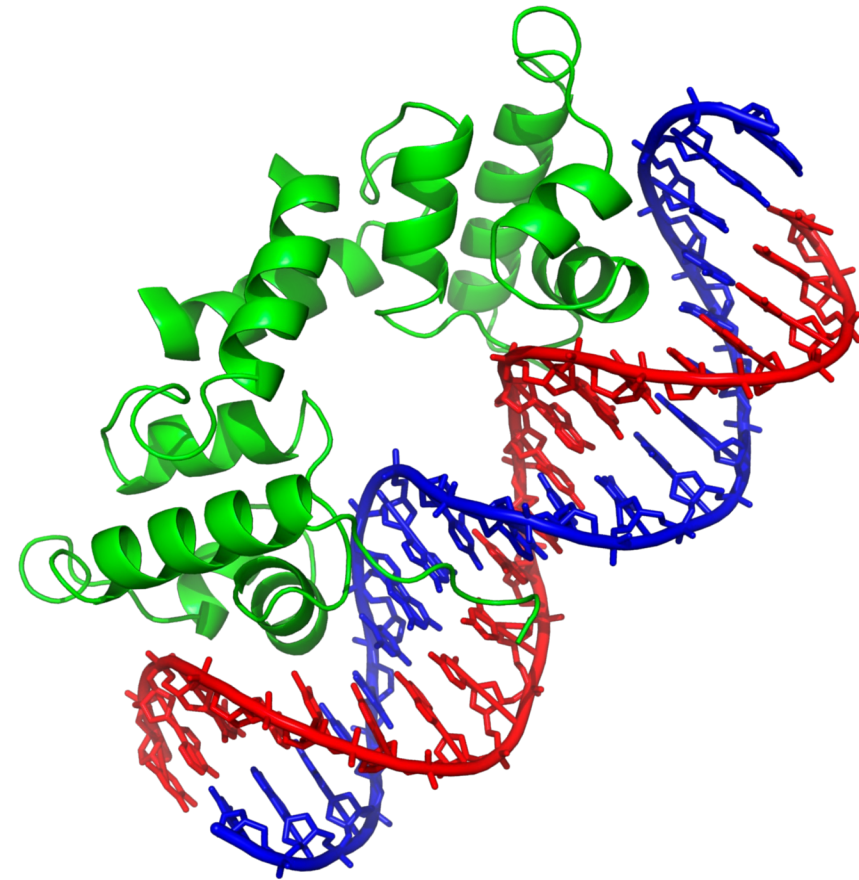


# Looking to the Future

## Research Infrastructure for Lipedema

**We need:**

- **Biomarkers**
- **Family studies**
- **Biorepositories**
- **Model systems**



wikipedia.com



# Biomarkers

Out of 39 metabolites examined, one in particular (pyruvic acid – involved in energy metabolism) distinguished Lipedema with high confidence. A potential biomarker? (Kempa, et al., DOI: 10.3390/ijms242417437)

M2 macrophages continue to be implicated in Lipedema in multiple studies, suggesting an immune/inflammatory component (Kruppa, et al.

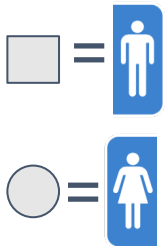
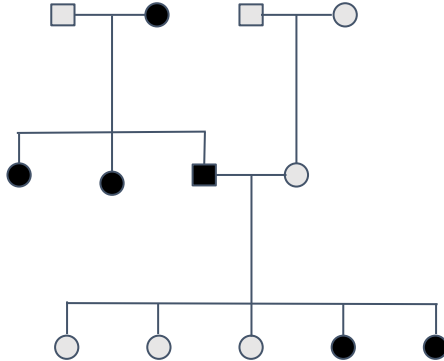
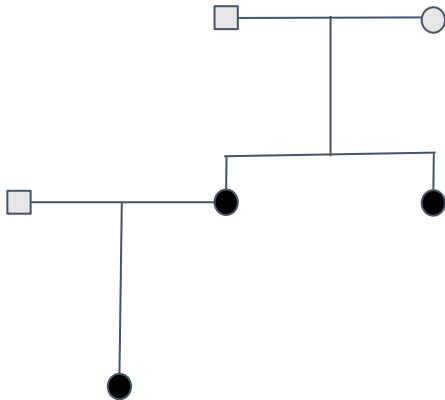
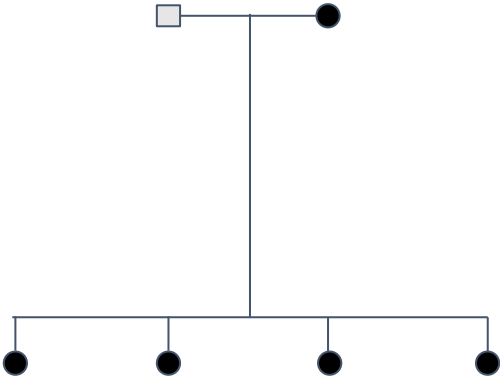
<https://www.frontiersin.org/articles/10.3389/fimmu.2023.1223264>, Von Atzigen et al. DOI: 10.3390/ijms24087591)

**See: <https://www.lipedema.org/blog/2024/1/24/2023-research-roundup>**

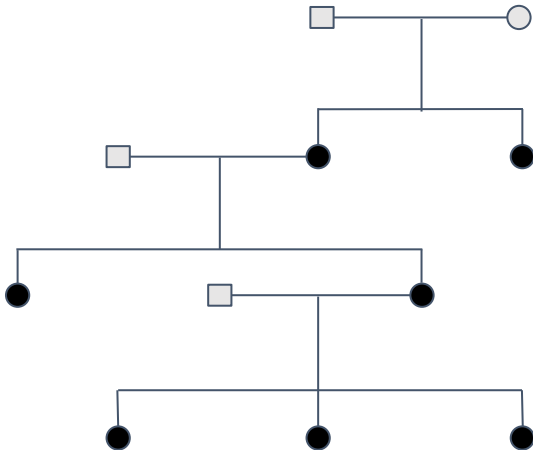


# Family Based Studies

Studying Lipedema in families can be informative



■ ● = Lipedema



**Ostergaard, P. and Pittman, A.**  
St. George's University of London

**Forner-Cordero, I.**  
Universidad de Valencia,  
Hospital Universitari i Politècnic La Fe

# Lipedema Biorepository



**Co-Principal Investigator: Rachelle Crescenzi, PhD**  
**Co-Principal Investigator: Aaron W. Aday, MD, Msc**  
*Vanderbilt University Medical Center, Nashville, TN*

**ClinicalTrials.gov ID NCT06180850**

There is no model system for Lipedema - *this biorepository is a vital resource*

This project, funded by LF, aims to advance the understanding and diagnosis of Lipedema

The biorepository will curate biological samples from clinically characterized patients with Lipedema and adults without Lipedema

This resource will test and generate new hypotheses that contribute to continuing Lipedema research





# Adipose Disorder: A Model System Example



Xu, et al. DOI 10.1016/j.cmet.2011.08.009

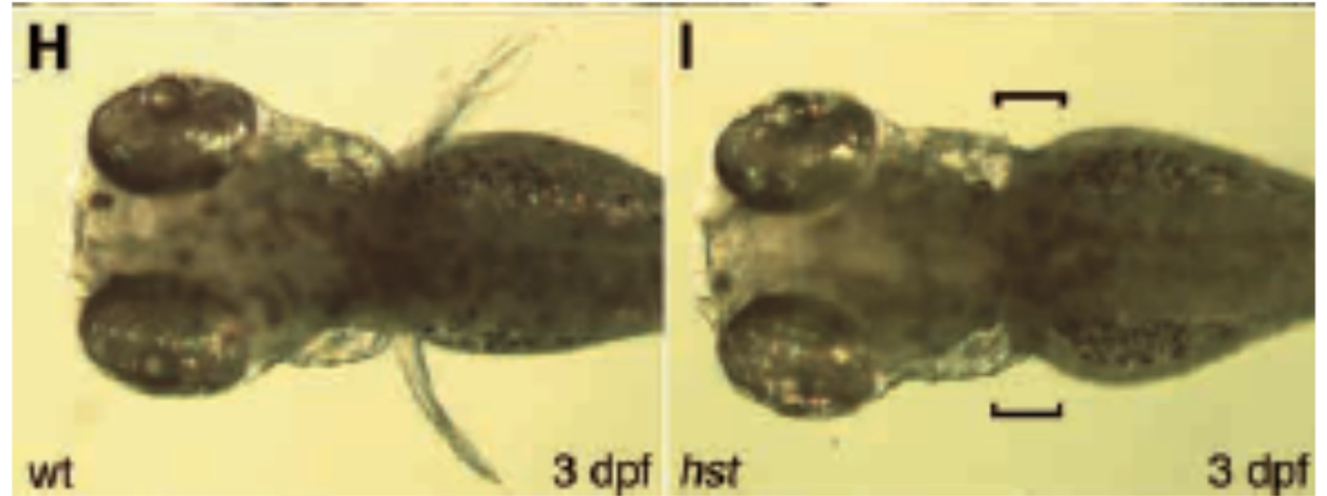
Could we study Lipedema in a mouse if we had a model?  
Model systems speed up research!

# What is a Model System?

## Holt-Oram Syndrome as an Example



Dawn Larson was born with Holt-Oram Syndrome, leaving her with underdeveloped hands and arms. (Richard A. Chapman/Sun-Times)



To understand what causes a disease, scientists often create a disease model – a biological system in the lab that mirrors a disease or shows some of the same disease processes.

(<https://www.embl.org/topics/disease-models/>)

# Take home lessons



- One of the largest studies on Lipedema symptoms validates patient experience - more work is need to evaluate intervention vs symptoms
- Lipedema pain is real - it is not in the mind, it can be quantitatively measured
- Nutritional interventions may be useful, but larger studies are needed
- Liposuction can lead to improvements in QoL
- Family histories can be highly informative
- The Lipedema Biorepository is a vital resource



*St. Louis*

**FDRS 2024**

April 19-21



# CONTACT INFORMATION

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