ABOUT THE LIPEDEMA FOUNDATION

Established in 2015, the mission of the Lipedema Foundation (LF) is to define, diagnose, and develop treatment for lipedema. Lipedema is a chronic condition that manifests as a symmetrical buildup of painful fat and swelling in the limbs, sparing the hands and feet. Limited understanding of disease biology, coupled with a lack of definitive diagnostic tools, has contributed to inadequate public, scientific, and medical awareness of the disease. To address these challenges, LF has committed more than $5 million toward building a new research field through training, proof-of-concept, and collaborative research awards.

RESEARCH EFFORTS AND GRANTEES

Despite initial reports and classification over 75 years ago, little is known about how and why lipedema develops. To better understand lipedema's basic biology, LF supports hypothesis-driven research aimed at exploring the various residents of lipedematous tissue with the goal of assessing their state and function compared to controls. We also support a series of patient-centered research efforts, including imaging and blood tests, exploration of the role of genomics, and surveys to capture the patient experience.

Since launching three years ago, the Foundation has published a disease landscape report, instituted several mouse models, and issued 22 awards. Our long-term vision is to support a series of patient-centered research efforts, including imaging and blood tests, exploration of the role of genomics, and surveys to capture the patient experience.

We also facilitate targeted collaborations through our Post-Poor program: Our genetics grantees — Natasha Harvey, Yann Klimantitis and Pia Ostergaard — are working to reduce barriers to research by sharing results and co-publication procedures. Epa Gousopoulos has also agreed to provide patient samples for Rene Haegerling's VIPAR project to image lipedema tissue.

The Lipedema Sandbox is a visualization of key stakeholders in the lipedema field. Through our research program, LF aims to serve as the collaborative hub that connects and facilitates interactions amongst all relevant stakeholders. Each color refers to an effort described in more detail in the poster.

The Lipedema Sandbox is a collaborative effort that will generate a well-diagnosed and phenotype group of 25 lipedema patients and controls. Participants will undergo multiple imaging studies, with samples collected by the University of Arizona disseminated to six basic research labs. The goal of the effort is to generate a comprehensive and comparable dataset of lipedema physiology.

ABOUT LIPEDEMA

Insight into Subcutaneous Adipose Tissue Disorders (INSIGHT, NCT02383277) — University of Arizona

Led by Dr. Karen Herbst PhD, MD. The University of Arizona TREAT Program is a first-in-kind multi-disciplinary group focused on lipedema and all adipose tissue disorders. It involves exceptional imaging programs, collaborative faculty, and the University of Arizona Biorepository.

Imaging Lymphatic Function in Normal Subjects and in Persons With Lymphatic Disorders (NCT00833599)

— University of Texas, Houston

Led by Dr. Eva Sevilk-Muraca, this study utilizes near-infrared fluorescence imaging to compare the real-time lymphatic flow of women with lipedema versus healthy controls.

Imaging Lymphatic Function for a Differential Diagnosis of Lipedema and Obesity (VUMC IRB #160199)

— Vanderbilt University Medical Center

Led by Dr. Maura Donahue, PhD, and Dr. Rachelle Crescenzi, PhD, this study utilizes Na-MRI and the calculated levels of sodium in the tissue in an effort to differentially diagnose lipedema patients from obese or individuals with lymphedema.

Effect of Weight Loss on Body Composition and Metabolic Function in Women with Lipedema (Lipedema, NCT17721462 — Washington University

Led by Dr. Samuel Klein, MD, and Dr. Vincenza Cifarelli, PhD, this study aims to generate a baseline characterization of lipedema, including body composition, fat distribution, adipose tissue biology, metabolic and immune function in affected individuals. Collection of characteristics will be followed by a Mediterranean diet intervention. This project is not funded by the Lipedema Foundation.

CLINICIANS AND CLINICAL STUDIES

Early Stage Investigators

• Anna Bauer (UW Madison)
• Bruce Rountree (UNC)
• Maura Donahue (the UK)
• Yann Klimantitis (genetics)
• Eva Sevilk-Muraca (disease biology)
• Carrie Shawber (accuracy)
• Melody Sweeney (accruals)

Post-doctoral Fellowships

• Eline Booms in Tom Peddread’s Lab (mouse lymphatics)
• Jason Labin-Freddo in Ainea Szymanski’s Lab (LEC biology)
• Kelly Kuehn in Pam Schneider’s Lab (adipose biology)
• Ali Shahazadeh in (Joe Rutkowski’s) Lab (mouse IRB)
• Kin To in Brandon Dixon’s Lab (mouse lymphatics)
• Andrea Zalucki in Peter Carmeliet’s Lab (LEC biology)

Model Systems and Research Samples

Given the unknown etiology of lipedema, we encourage research efforts that utilize patient samples such as: blood, tissue biopsies, and adipose samples. Patient samples are currently collected and banked by three collaborative LF grantees: Karen Herbst USA, Epa Gousopoulos Germany, and Natasha Harvey Australia.

In the absence of known targets, we also support animal models that address and phenotypic characteristic of lipedema including: A) in vivo drug FR alpha knockdown (Michelle Foster); B) SAT deposition (Carrie Shawber); C) VEGF-expression in adipocytes (Joe Rutkowski); D) Calcium pumping and lymph flow (Brandon Dixon).

CLINICIANS AND CLINICAL STUDIES

Established Investigators

• Lea Bower (UMBC)
• Bruce Rountree (UNC)
• Maura Donahue (the UK)
• Yann Klimantitis (genetics)
• Eva Sevilk-Muraca (disease biology)
• Carrie Shawber (accuracy)
• Melody Sweeney (accruals)

Early Stage Investigators

• Anna Bauer (UW Madison)
• Bruce Rountree (UNC)
• Maura Donahue (the UK)
• Yann Klimantitis (genetics)
• Eva Sevilk-Muraca (disease biology)
• Carrie Shawber (accuracy)
• Melody Sweeney (accruals)

Post-doctoral Fellowships

• Eline Booms in Tom Peddread’s Lab (mouse lymphatics)
• Jason Labin-Freddo in Ainea Szymanski’s Lab (LEC biology)
• Kelly Kuehn in Pam Schneider’s Lab (adipose biology)
• Ali Shahazadeh in (Joe Rutkowski’s) Lab (mouse IRB)
• Kin To in Brandon Dixon’s Lab (mouse lymphatics)
• Andrea Zalucki in Peter Carmeliet’s Lab (LEC biology)

Cytometry

— Blood biomarkers and imaging modalities — Genomics — Quality of Life

INTERSTITIAL FLUID

BLOOD VESSELS

ADIPOCYTE STEM CELLS

FIBROUS

NERVES

IMMUNE CELLS

EXOSOMES

ADIPOCYTES

LYMPHATIC VESSELS

LYMPHATIC VESSELS

PATIENT-CENTERED RESEARCH

Blood biomarkers

Imaging modalities

Genomics

Quality of Life

IMAGING LIPEDEMA

Patient 1

Stage 1 lipedema

Patient 2

Stage 2 lipedema

Patient 3

Stage 3 lipedema

Post-Poor Program

• Natasha Harvey (Australia)
• Yann Klimantitis (genetics)
• Pia Ostergaard (genetics)
• Rene Haegerling (VIPAR)
• Eva Sevilk-Muraca (NIRFLI)
• Melody Swartz (exosomes)

GRANTEES

ABOUT THE LIPEDEMA FOUNDATION

Diagnosis of lipedema — which occurs almost exclusively in women — is usually based on clinical features, including:

1. Bilateral and symmetrical accumulation of adipose tissue (body fat) on the legs with minimal involvement of the feet, resulting in a bracelet effect or cuff at the ankle
2. Minimal pitting edema and negative Stemmer’s Test
3. Pain and tenderness of affected tissue
4. Increased vascular fragility with easy bruising
5. Persistence of the tissue enlargement despite caloric restriction or stimulation of lymphatic flow through elevation of the extremities.

Lipedema Type describes the areas of the body with fat, while Stages indicate the level of fat accumulation and related comorbidities. A) Front and back images of Type 1, Stage 1 lipedema. B) Front and back images of Type 1, Stage 2 lipedema. C) Front and back images of Type 1, Stage 2 lipedema. D) Front and back images of Type 1, Stage 3 lipedema. E) Front and back images of Type 1, Stage 2 lipedema. F) Front and back images of Type 1, Stage 3 lipedema. G) Front and back images of Type 1, Stage 3 lipedema. H) Front and back images of Type 1, Stage 3 lipedema. I) Front and back images of Type 1, Stage 3 lipedema. J) Front and back images of Type 1, Stage 3 lipedema. K) Front and back images of Type 1, Stage 3 lipedema. L) Front and back images of Type 1, Stage 3 lipedema. M) Front and back images of Type 1, Stage 3 lipedema. N) Front and back images of Type 1, Stage 3 lipedema.

CLINICIANS AND CLINICAL STUDIES

INSIGHT INTO SUBCUTANEOUS ADIPOSE TISSUE DISORDERS (INSIGHT, NCT02383277) — University of Arizona

Led by Dr. Karen Herbst PhD, MD. The University of Arizona TREAT Program is a first-in-kind multi-disciplinary group focused on lipedema and all adipose tissue disorders. It involves exceptional imaging programs, collaborative faculty, and the University of Arizona Biorepository.

Imaging Lymphatic Function in Normal Subjects and in Persons With Lymphatic Disorders (NCT00833599)

— University of Texas, Houston

Led by Dr. Eva Sevilk-Muraca, this study utilizes near-infrared fluorescence imaging to compare the real-time lymphatic flow of women with lipedema versus healthy controls.

Imaging Lymphatic Function for a Differential Diagnosis of Lipedema and Obesity (VUMC IRB #160199)

— Vanderbilt University Medical Center

Led by Dr. Maura Donahue, PhD, and Dr. Rachelle Crescenzi, PhD, this study utilizes Na-MRI and the calculated levels of sodium in the tissue in an effort to differentially diagnose lipedema patients from obese or individuals with lymphedema.

Effect of Weight Loss on Body Composition and Metabolic Function in Women with Lipedema (Lipedema, NCT17721462 — Washington University

Led by Dr. Samuel Klein, MD, and Dr. Vincenza Cifarelli, PhD, this study aims to generate a baseline characterization of lipedema, including body composition, fat distribution, adipose tissue biology, metabolic and immune function in affected individuals. Collection of characteristics will be followed by a Mediterranean diet intervention. This project is not funded by the Lipedema Foundation.

Researchers

Surgery

Clinicians

Patients

Surgeons

Lipede Research Foundation, Greenwich, CT, USA

JOIN OUR EFFORT! lipedema.org

Share your research interests: info@lipedema.org

TO YOUR PATIENT REGISTRY!

To further involve patients in our efforts, and collect uniform data, the Foundation will launch a lipedema patient research registry in 2018. The registry will:

• Collect basic demographic information of individuals affected by lipedema
• Generate a database of affected individuals interested in research participation
• Collate and disseminate the phenotype and comorbidities of lipedema

MODEL SYSTEMS AND RESEARCH SAMPLES

Given the unknown etiology of lipedema, we encourage research efforts that utilize patient samples such as: blood, tissue biopsies, and adipose samples. Patient samples are currently collected and banked by three collaborative LF grantees: Karen Herbst USA, Epa Gousopoulos Germany, and Natasha Harvey Australia.

In the absence of known targets, we also support animal models that address and phenotypic characteristic of lipedema including:

A) In vivo drug FR alpha knockdown (Michelle Foster); B) SAT deposition (Carrie Shawber); C) VEGF-expression in adipocytes (Joe Rutkowski); D) Calcium pumping and lymph flow (Brandon Dixon).