

AMERICAN LIPEDEMA ASSOCIATION

NEWSLETTER

SEPTEMBER 2024

VOL. 01 / ISSUE 01

Welcome...

The American Lipedema Association is dedicated to advocating for and empowering individuals in the United States affected by lipedema.

Our current focus has been on getting Lipedema added to the ICD-10 codes, since we have no idea when the ICD-11 codes will go into effect. We hope you will join us live on September 21 at 4pm CDT / 5pm EDT for a webinar to learn more about this work, and how you can get involved.

PATIENT SPOTLIGHT HELEN GUILFORD

My name is Helen Guilford. I'm 68 years old. I self- diagnosed my lipedema after finding Siobhan Huggins on Dr Ken Berry and Dr. Shawn Baker's podcasts. I started following people dealing with this disease on YouTube. I have been dealing with back pain off and on and over the last 2 years, increased leg pain with difficulty walking. I bruise easily, I have cuffing, I set the alarms off at the airport, boots never fit my calves and multiple lipomas over my body. I had one knee replacement and will probably need a second. I have venous insufficiency and am looking at ablation soon. I educated my family doctor, chiropractor and knee surgeon, giving handouts from the Lipidema organization. I reached out to two plastic surgeons in my area, and they are not aware of the disease. I leave pamphlets in doctors' offices. I am on a 2 month waiting list for a local clinic treating lipedema. More education to providers is needed, increased awareness to women to help deal with this and increased funding for treatment and research as this disease can be debilitating. As a retired RN, I gave some information to my colleague friend now teaching nursing students and he promised to include the topic in his classes.



MEMBERSHIP INFO TO DATE:

75 MEMBERS FROM 34 STATES

- 5 ORGANIZATIONS
- 3 SCHOLARSHIPS - 67 PATIENTS



AMERICAN LIPEDEMA ASSOCIATION

Weet the Board of Trustees...

SUSAN O'HARA PRESIDENT

Susan O'Hara is from Yukon. OK. She is 51 years old and has had lipedema since giving birth to her first child 23 years ago, and was diagnosed 4 years Susan has written ago. numerous books about lipedema and manages LegsLikeMine.com along with a small startup company that makes shoes for late stage lipedema patients. Susan believes that a unified patient group makes us stronger to advocate with a big voice and is very happy to see as much this movement vear lipedema advocacy overall - it's an exciting time!



TRUSTEE Pattie Cornute is a Patient.

PATTIE CORNUTE

Advocate and the Founder of Lipedema Fitness, a patient support group that iust celebrated their 10 vear anniversary last year, and has grown to over 16,000 members strong. In addition to patientfocused advocacy. Pattie spreads awareness publicly by speaking to medical professionals and patients alike at various conferences. hosting monthly lives with various special guests, and cothe monthly anchoring Lipedema Patient Roundtable. hosted by Lympha Press.



Amplifying our Voices by (Initing!

DR. THOMAS WRIGHT TRUSTEE

Dr. Thomas Wright has written over 12 Scientific abstracts and peer-reviewed publications, incl. 9 peer-reviewed manuscripts lipedema in the last 3 years. He recently published his research outlining improvements lipedema patients' quality of life following Lipedema Reduction Surgery LRS. He is a co-author of the US lipedema Standard of Care and he authored case reports of lipedema coexisting with anorexia nervosa and lipedema coexisting with malnutrition. He was trained in the tumescent liposuction technique by its originator, Dr. Jeffrey Klein. Dr. Wright has performed thousands tumescent liposuction procedures for cosmetic and lipedema patients, and developed his own lymphatic-sparing surgical technique using micro cannulas to limit unnecessary injury to the lymphatics.

