

# Learning by Listening: The LF Registry First Look Report

An executive summary of the findings of the Lipedema Foundation Registry survey

In early 2019, the **Lipedema Foundation**, in partnership with advisors from the Lipedema patient and research communities, launched the Lipedema Foundation Registry — an initial confidential survey to help better understand the condition. We have published the findings in the *Learning By Listening: The LF Registry First Look Report*.

The 16-page report offers a perspective on the diverse experiences of people with Lipedema. It includes data from the first 521 fully-completed Registry surveys from people who believe they have Lipedema, out of 2,000 in-progress responses.

This executive summary highlights the key findings of the *LF Registry First Look Report*, which is consistent with academic literature and findings.

Among the findings:

- **Symptoms often appear during puberty:** Almost 58% of participants first noticed Lipedema symptoms between the ages of 10-19 years, most between ages 12 and 14
- **Hormones may play a role:** 10% of participants experienced first symptoms around other times of hormonal change, such as pregnancy (4.5%), and menopause (5.5%)
- **Long delays between onset and treatment:** Although Lipedema may appear early in life, the average age of diagnosis is 48 years old, and women sought medical attention 17 years after first noticing symptoms
- **No standard path to diagnosis:** Most participants (59%) had received a diagnosis from one or more health care professionals. Of these, 63% had received a diagnosis from a non-surgeon medical doctor. About a third (32%) had received a diagnosis from a surgeon
- **Consistent pain:** Average daily pain for most participants was five on a 10-point pain scale
- **Top symptoms are leg heaviness, fatigue, and easy bruising:** These symptoms occur with frequency and some severity, with leg heaviness (65%), fatigue (54%), and bruising (50%) reported as being “very severe”
- **Runs in families:** Nearly all (94%) of the participants report a family history of Lipedema

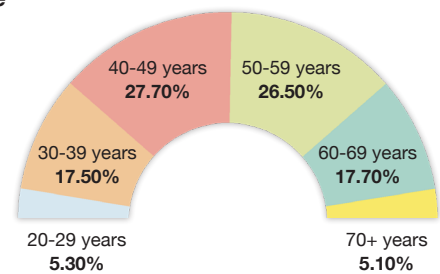
Analysis of patient experience reminds us that Lipedema can present in many ways — Lipedema is not defined by one person’s experience, but many. Consider sharing this report with healthcare providers that may not be aware of Lipedema and with patient communities that are currently underrepresented in this data.

For more information about the *LF Registry First Look Report* or to download a copy, click [here](#).

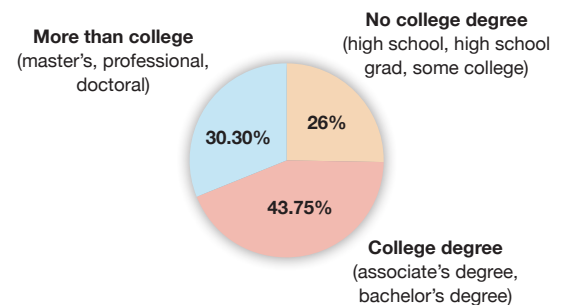
The Lipedema Foundation is the world’s largest funder of Lipedema research. Our mission is to define, diagnose and develop treatments for Lipedema. [Learn more.](#)

## DEMOGRAPHICS

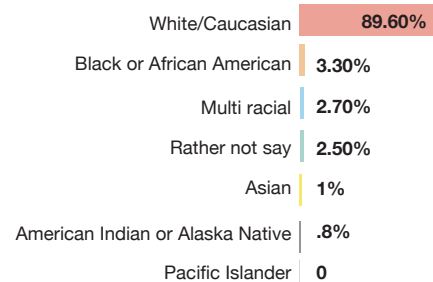
### Age



### Education



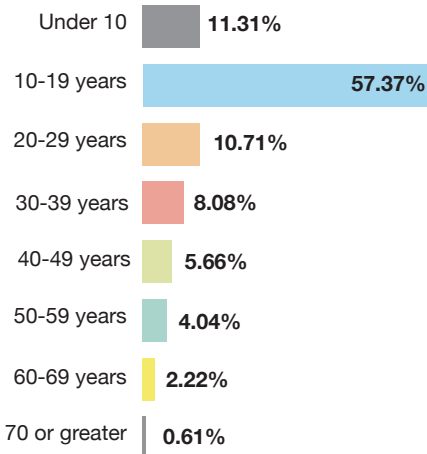
### Race



## FIRST SIGNS

People with Lipedema often first notice symptoms around times of hormonal change. More than half of participants (57%) reported the first signs of Lipedema around puberty (during the teenage years) with peak onset of symptoms between ages 12 and 14. Another 10% reported first symptoms around pregnancy (4.5%) and menopause (5.5%).

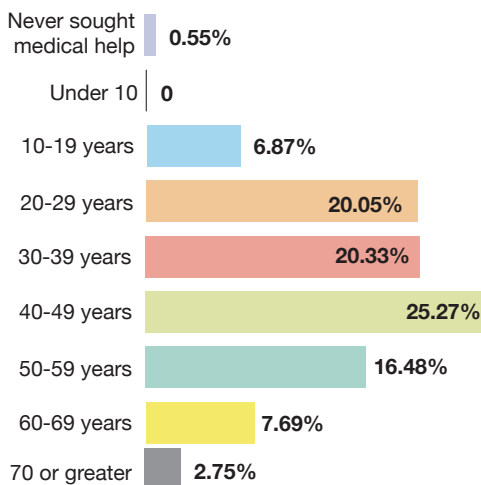
### Age when Lipedema starts



## SEEKING HELP

Although Lipedema typically appears early in life, the average age of diagnosis for participants is 48 years old, with an age range of 13 to 77 years. On average, participants took 17 years to seek medical attention after first noticing systems. Once engaged with healthcare professionals, it took participants another 10 years before receiving a medical diagnosis of Lipedema.

### Age when medical help is first sought



## CO-MORBIDITIES BESIDES OBESITY

Obesity is the most common self-reported condition to exist alongside Lipedema, present in 73% of the participants. Interestingly, diabetes, at 6%, was present at a lower rate than would be expected, given the level of obesity. This chart reflects the percentage of co-morbidities as indicated by participants.

Irritable Bowel Syndrome (IBS) 20%

Spider Veins 48%

HPV Infection 16%

Other Autoimmune Disorders 23%

Hypothyroid 27%

High Blood Pressure 26%

Anemia 39%

Lymphedema 29%

Poly Cystic Ovarian Syndrome 13%

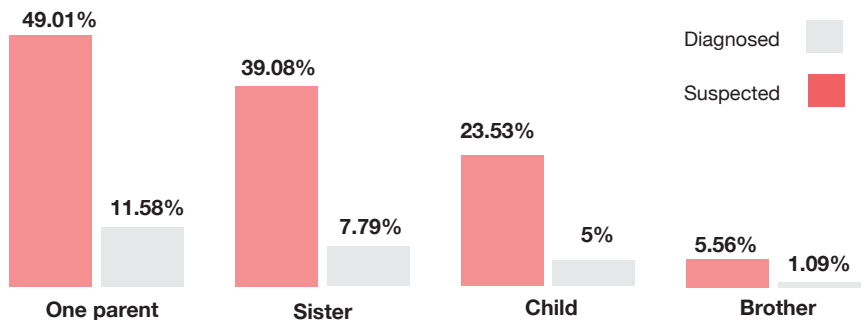
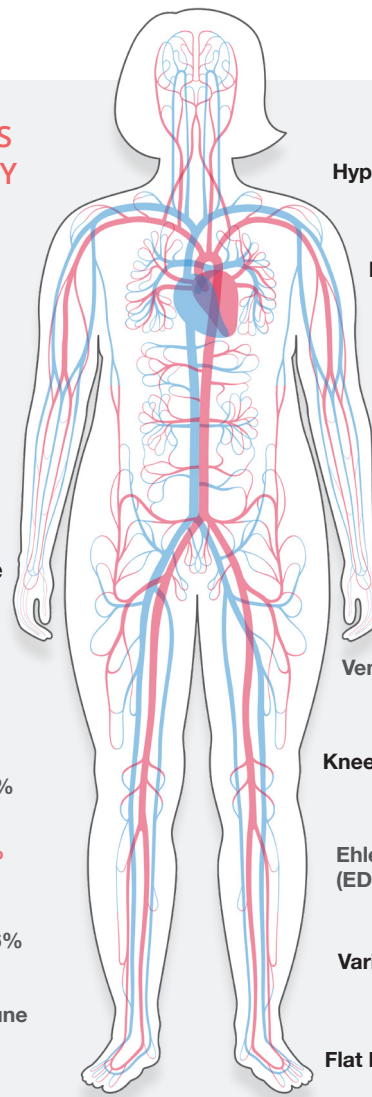
Venous Insufficiency 19%

Knee Problems 54%

Ehlers Danlos Syndrome (EDS) – Hypermobility 12%

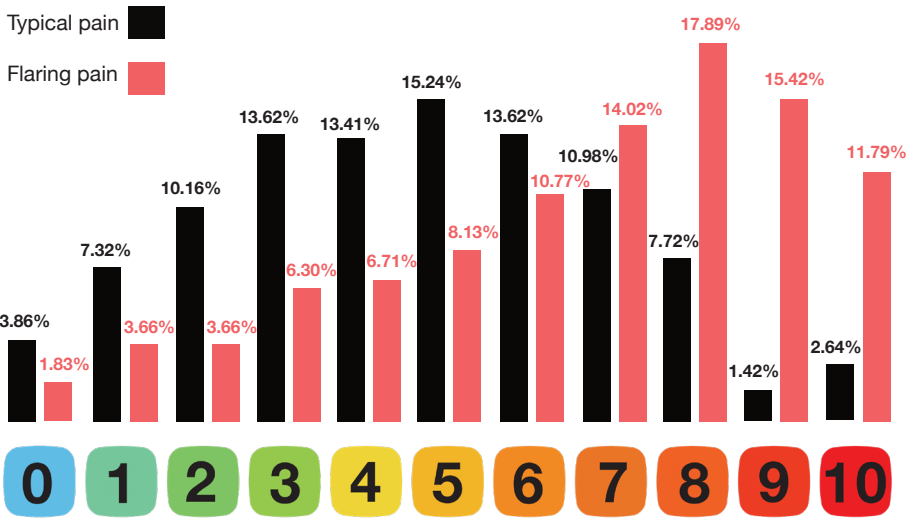
Varicose Veins 38%

Flat Feet/Fallen Arches 29%



## FAMILY HISTORY

While no single gene has been confirmed to affect the risk of developing Lipedema, patients are likely to have a close relative with the condition. Only 15% of the participants have an immediate family member that has been diagnosed with Lipedema, but undiagnosed Lipedema is suspected in 56% of cases overall. Interestingly, 6% of the participants with blood-related male siblings suspect the presence of Lipedema in at least one of those male siblings.

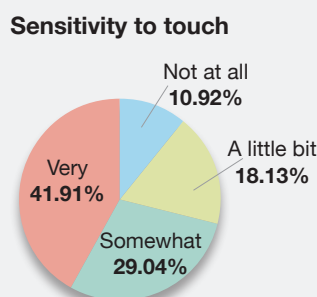
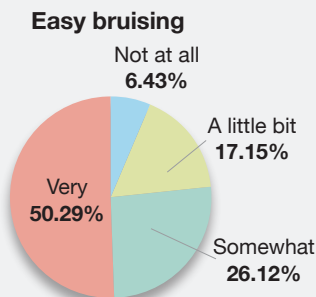
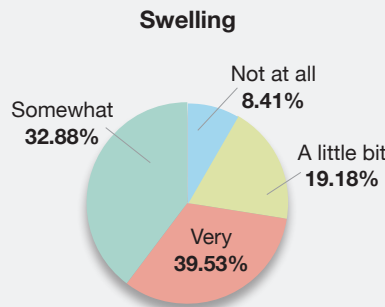
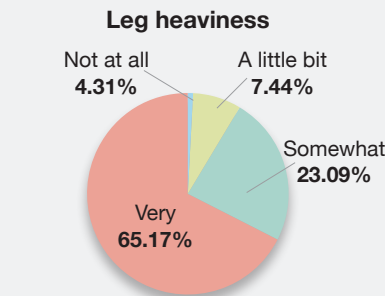
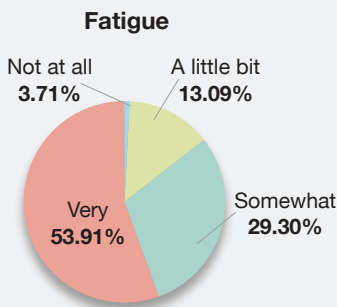


### PAIN IS A HALLMARK OF LIPEDEMA

Life with Lipedema involves consistent pain for most people with the condition. Average daily pain for most participants was five on a 10-point scale, suggesting that pain can be managed but not ignored. Participants report daily flaring pain at an average of seven on a 10-point scale, suggesting a level of pain capable of interfering with sleep and other activities. Only 4% of participants reported no pain on a typical day.

### COMMON SYMPTOMS

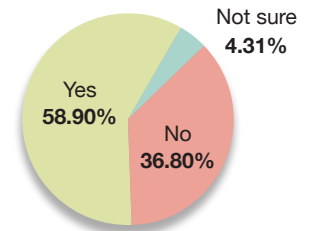
Lipedema's hallmark symptoms – fatigue, sensitivity to touch, easy bruising, leg heaviness and swelling – occur with frequency and some severity for participants. We asked how severe these conditions were for them for the past 30 days, and these were their responses.



### GETTING A DIAGNOSIS IS COMPLICATED

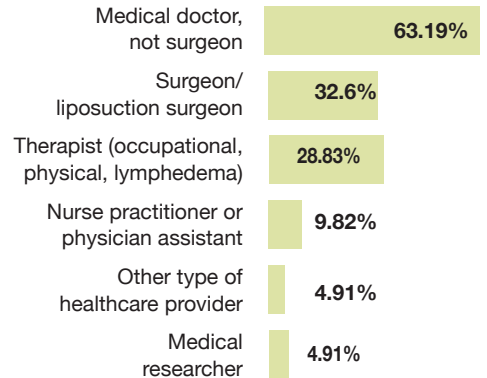
Lipedema is diagnosed by a diverse and fragmented array of healthcare professionals. Almost 60% of participants were diagnosed by one or more healthcare professionals, with non-surgical medical doctors, surgeons and therapists topping the list. For the 37% that were not diagnosed by a healthcare professional, the majority (81%) were self-diagnosed, based on their own research on Lipedema.

Were you diagnosed by a healthcare professional?



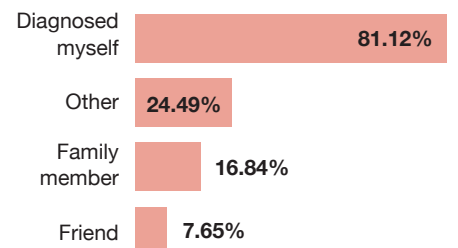
Participants were formally diagnosed by the following healthcare providers:

(Note: Multiple responses accepted)

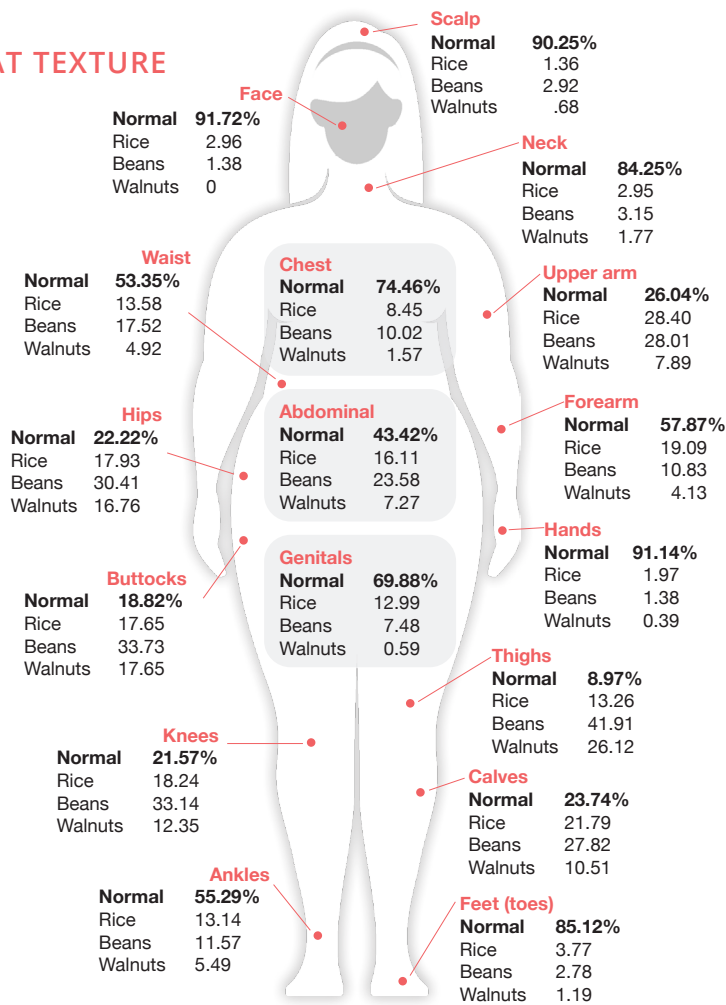


Participants who believe they have Lipedema but were not formally diagnosed by a healthcare professional:

(Note multiple responses accepted)



## FAT TEXTURE

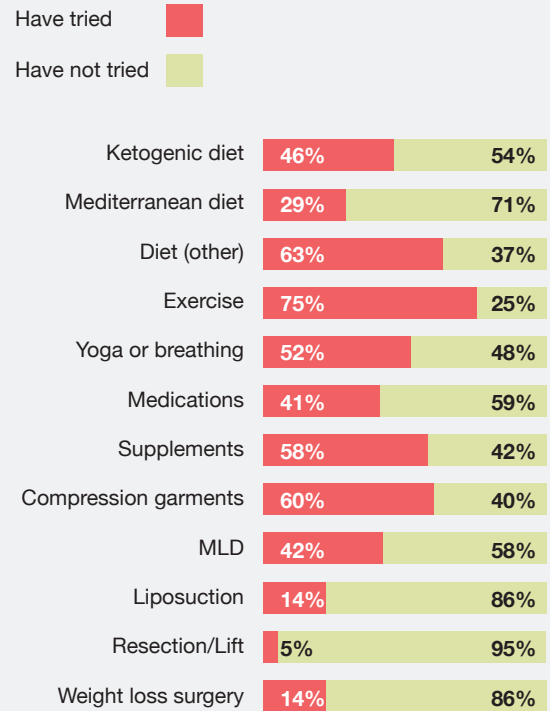


Participants were asked “How would you describe how the fat feels in your body?” Lipedema-like texture can be found throughout the body, with varying frequency. It is often described as having the texture of rice, beans and walnuts. Though most common in the hips, buttocks, legs and upper arms, Lipedema-like texture occurs elsewhere, although less commonly.

## TREATMENTS HELP MANAGE SYMPTOMS, BUT OFFER NO CURE

While treatments help to manage symptoms, no therapy offers a cure. However, participants have tried many treatments, particularly those with lower cost barriers and that can be done at home.

Treatments tried (n=521)



## STAGING - IS LIPEDEMA PROGRESSIVE?

Despite reports in medical literature that claim Lipedema does not progress over time, findings from the *LF Registry First Look Report* suggest that staging does seem to correspond with the duration of the condition. Many people with Lipedema report that texture, nodules, and other Lipedema features appear and change over the course of many years.

\*Since the launch of the Registry in early 2019, the concept of Stage 4 Lipedema/ Lipolymphedema has been challenged in the medical community. One argument is that the functioning of the lymphatic system can be compromised by Lipedema at any stage. This conversation is ongoing, and the Registry data related to staging is reported here in the manner that it was collected.

### Relationship between stage and number of years living with Lipedema

(# of years living with Lipedema = age when respondent completed the Registry – age when Lipedema symptoms began)

	< 10 years (n = 52)	10-19 years (n = 82)	20-29 years (n = 121)	30-39 years (n = 119)	40 > years (n = 121)
Less than stage 1	1.92	0	0	0	0.83
Stage 1 (Smooth skin; increase of enlarged subcutaneous fat tissue)	17.31	14.63	4.96	5.04	4.13
Stage 2 (Uneven skin; larger nodules or lipomas seen and felt)	36.54	29.27	42.98	36.13	33.88
Stage 3 (Larger extrusions of fat tissue causing deformations around thighs and knees)	17.31	15.85	14.05	27.73	33.88
Stage 4/ Lipolymphedema* (Lipedema & lymphedema both present; large tissue overhangs)	1.92	0	8.26	6.72	8.26
Stage not diagnosed (Patient was diagnosed but not given a stage)	9.62	25.61	16.53	13.45	13.22
I don't know	15.38	14.63	13.22	10.92	5.79