

FIRST
LOOK

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Living with Lipedema

Early findings of the Lipedema Foundation Registry survey.



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Charting a new era in Lipedema research

In early 2019, the Lipedema Foundation, in partnership with advisors from the Lipedema patient and research communities, launched the Lipedema Foundation Registry — a confidential survey to help understand the condition. After three years, we are ecstatic to share this Registry First Look report, providing perspective on the diverse experiences of people with Lipedema.

We are tremendously thankful to those who contributed their time and insights, without which this report would not have been possible.

This report includes data from the first 521 fully completed Registry surveys from people who believe they have Lipedema, out of 2,000 in-progress responses.

These 521 people represent 14,556 years of lived experience with Lipedema, across dimensions including:

- **Diagnosis:** This report focuses on the experiences of 521 people who either report having received a Lipedema diagnosis, or have symptoms sufficient for them to believe they have Lipedema. Data from non-Lipedema populations has been collected, but is not presented in this report.

- **Amount of time living with Lipedema:** Participants include women with less than 10 years duration of the condition, though almost half of survey respondents had lived with Lipedema for more than 30 years at the time of participation.

- **Geography:** Though only in English at this time, the Registry is multinational, with 21% of contributions from outside the US.

Much captured here is consistent with existing academic literature and surveys.

Findings include:

- The Registry data is consistent with research showing the majority of patients first notice symptoms around the time of puberty; more specifically, the Registry data shows peak onset of symptoms between ages 12 and 14.

- As widely reported by patients, this data

shows long delays between onset and treatment. On average, women sought medical attention 17 years after first noticing symptoms, and received a diagnosis 10 years later.

- Participants were able to identify Lipedema-like features in their bodies at frequencies consistent with the medical literature. They found Lipedema-like texture throughout their bodies, though most frequently in the arms and legs.

- Both typical and flaring pain are common. Heaviness, bruising, and sensitivity to touch are also common and speak further to patients' quality of life.

After analyzing the data, the Lipedema Foundation team conducted two focus groups with patients to help understand and contextualize the findings. Their interpretations, insights and quotes appear throughout.

Though this report is a great start, we hope it can be a tool to advance Lipedema awareness, understanding and care. Key next steps include:

- Challenging healthcare professionals to recognize and understand Lipedema, and stop stigmatizing and dismissing patients when they seek care.

- Informing scientific hypotheses and the research agenda.

- Expanding and diversifying Registry participation, to ensure it represents the true diversity of the Lipedema patient population.

Analysis of patient experience reminds us that Lipedema can present in many ways. This diversity asks us to take a closer look at typical descriptions of Lipedema, and this report should influence how we think about anatomical changes in Lipedema and progression of the disorder.

These insights must be followed up with formal medical studies, but many hypotheses to be tested have been captured here in the patients' own voices.

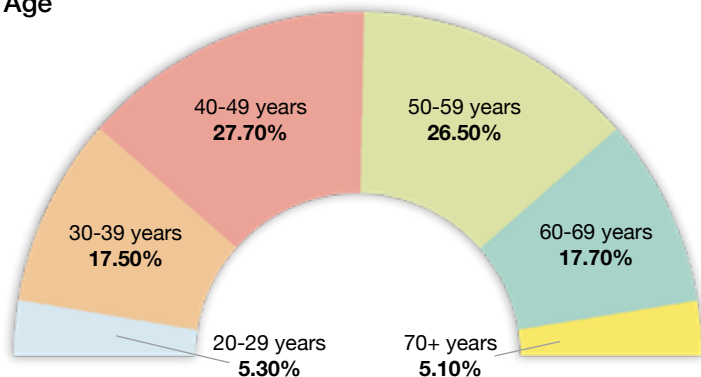
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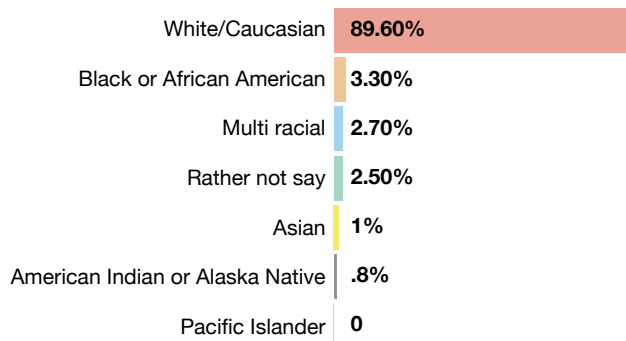
DEMOGRAPHICS

Lipedema knows no boundaries — crossing many demographic categories

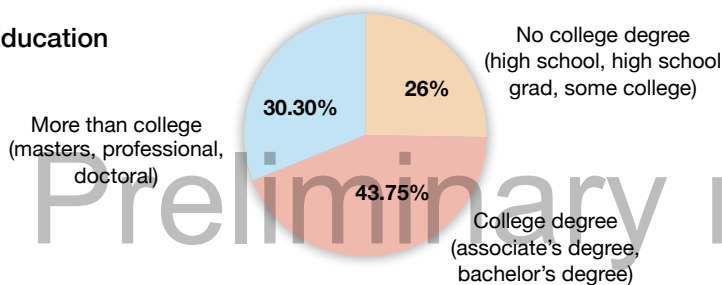
Age



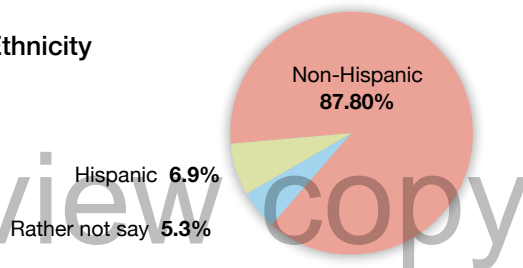
Race



Education



Ethnicity



Lipedema by the numbers

This report analyzes the experiences of the first 521 people with Lipedema to complete the initial Lipedema Foundation Registry survey between March 1, 2019 and February 4, 2022. Participants were recruited through the Lipedema Foundation website, email newsletters, and at patient conferences such as the annual Fat Disorders Resource Society (FDRS) conference. (More than 2000 people have either completed or started the survey as of early February 2022).

Their data is suggestive of the diversity that exists amongst individuals affected by the condition.

Lipedema can be found in any demographic category examined. It crosses age, educational background, body type and even gender. Although fewer than 10 case studies of men with Lipedema are reported in the medical literature, three self-reported cases of doctor-diagnosed male Lipedema are reported here.

Body Mass Index (BMI) is a frequently used metric in almost all Lipedema studies and many studies of metabolic disorders, but it is a problematic metric in Lipedema. Recent studies like [Crescenzi 2018] have shown that Lipedema may alter

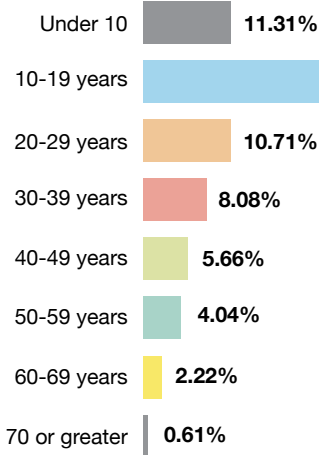
muscle to fat ratios, relative to women with the same BMI but without Lipedema. While BMI is reported here, it should be interpreted with caution. In this study, 9.2% were of BMI < 25 (kg/m²), 16.6% were between 25 and 30, and 74% had BMI > 30. It is notable that, though some in the research and medical communities conflate Lipedema with obesity, Registry respondents with Lipedema include both obese and non-obese patients as measured by BMI.

Like most health surveys, the Lipedema Foundation Registry disproportionately collects information from white, college-educated participants. In this study, many groups, including and especially racial and ethnic minorities, are underrepresented relative to their proportion in the population at large. This analysis, however, represents one of the largest aggregations of their unique experiences with Lipedema.

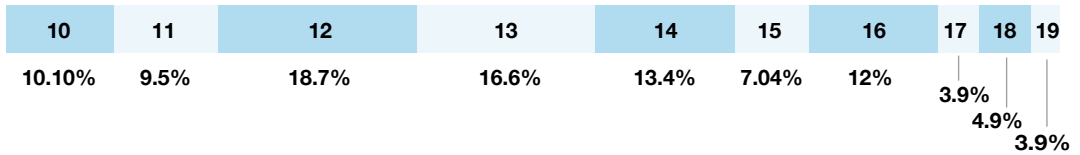
If you do not see your personal story reflected in this initial Registry analysis, we hope you will participate in the survey. Your contribution can improve our ability to understand the diversity of experience with Lipedema, including both biological and social contexts, that influence the impact of Lipedema in our communities.

Many years between onset of symptoms and medical treatment

Age when Lipedema starts



Breakdown of 10-19 years old (by age)



“ Everyone is different. For me, after my son was born, I couldn't understand why I couldn't lose the weight. I started to question what was going on. ”
 —Focus Group Participant

First signs

Registry data is consistent with existing academic studies that suggest the majority of Lipedema patients first notice symptoms around the time of puberty (during the teenage years). The Registry shows the onset during the teenage years more granularly, noting peak reporting of symptom onset between ages 12 and 14.

Data from 511 participants suggest that about 10% of participants experience first symptoms around other times of hormonal change, such as pregnancy (4.5%), and menopause (5.5%).

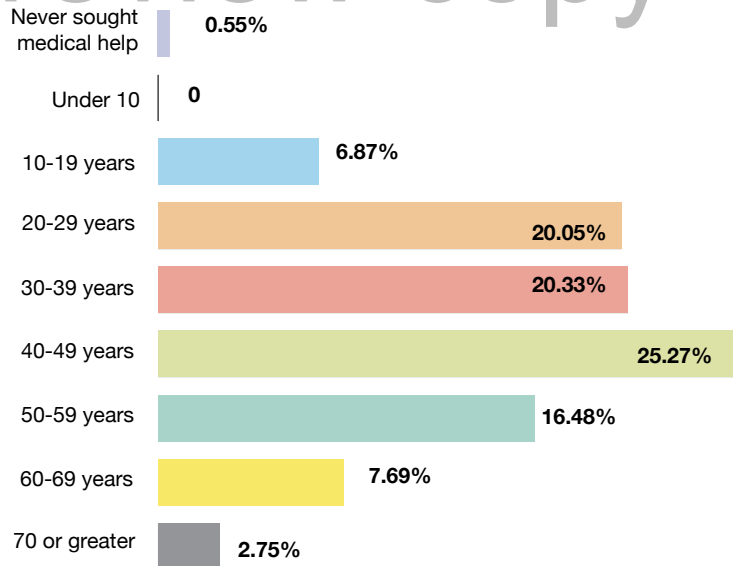
In what appears to be a new finding in medical literature, Registry data reports that in the infrequent cases where Lipedema symptoms started below the age of 10 (11% of respondents), nearly all (94%) of the women also report a family history of Lipedema.

Seeking help

Although Lipedema may appear early in life, the average age of diagnosis in the Registry sample is 48 years old, with a range of 13 to 77 years (n=280). On average, women sought medical attention 17 years (range 1-59) (n=320) after first noticing symptoms.

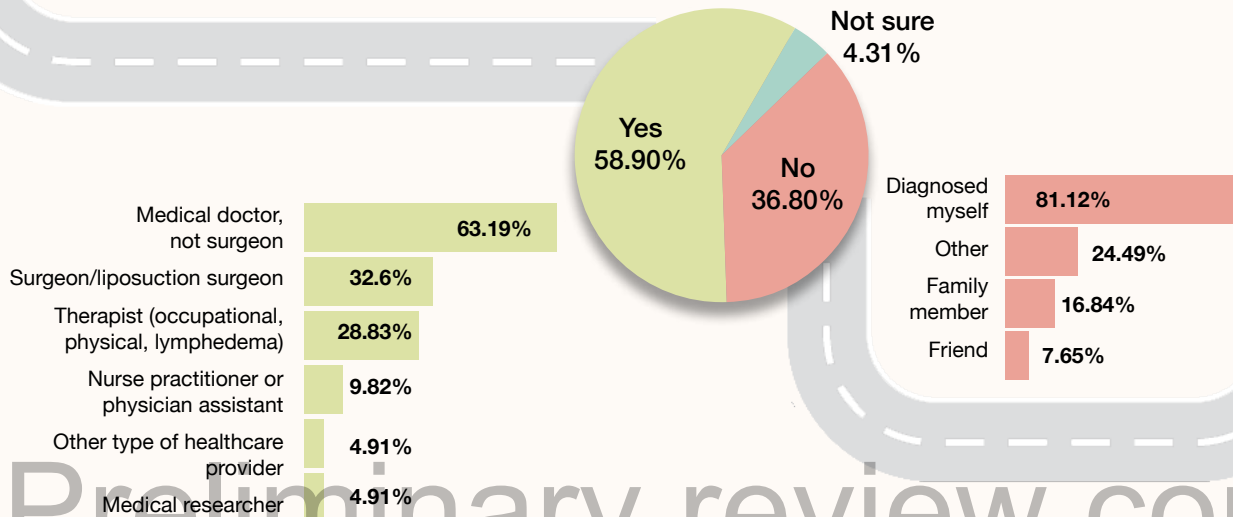
Once respondents first engaged with the medical system, a Lipedema diagnosis required, on average, 10 additional years (range 1-49) (n=169). This finding is consistent with other published studies that found similar delays for participants in receiving a Lipedema diagnosis [Bauer 2019].

Age when medical help is first sought



The path to diagnosis is not consistent across individuals

Were you diagnosed by a healthcare professional?



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Note: Numbers in the bars add to more than 100% because respondents were able to select more than one response.

Which medical professionals are diagnosing Lipedema?

Lipedema is being diagnosed by a diverse and fragmented array of health care professionals.

Most participants in the Registry (59%) had received a Lipedema diagnosis from one or more health care professionals. Of these 328 cases, 63% had received a diagnosis from a non-surgeon medical doctor. Approximately a third (32%) had received a diagnosis from a surgeon.

More than a third (39%) reported that their condition had been independently or additionally identified by an allied health care practitioner other than a doctor (e.g., nurse practitioner, therapist) or other member of the health care professional community.

Less than a third of participants received a Lipedema diagnosis from multiple health care professionals.

In absence of a professional diagnosis, women rely on themselves

About 81% of women who have not yet received a professional diagnosis believe they have Lipedema based on their own research. In some cases, friends (7.7%), and family (16.8%) were responsible for the participants becoming aware of the condition.

Lipedema care may be changing as awareness increases

Registry data analyzed so far suggests difficulty and delay in getting a Lipedema diagnosis. Patient focus groups who reviewed this document repeatedly noted an anecdotal observation that younger generations today may be encountering less difficulty in getting a diagnosis than older registry participants, as awareness of Lipedema becomes more prevalent. This observation merits further study.

Staging corresponds with duration of Lipedema

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

*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.

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What does staging tell us?

Some reports in the medical literature claim that Lipedema does not progress over time, and that changes to the body in patients with Lipedema are a result of obesity. This idea may seem surprising to many people with Lipedema who have watched nodules or other Lipedema features appear and change over the course of many years. Indeed, the above analysis of the Registry data appears to indicate that stage does correlate with the amount of time since onset of symptoms.

The concept of Lipedema stages was introduced to highlight long-known differences in the texture of skin. These changes differentiate Lipedema from more common, and often co-morbid, conditions like obesity, where the texture is generally smooth and lacks these knotty, dense features [Rank 1964, Ströbenreuther, R. and Baumeister, R.G.H. 2001, 2004].

Data from the Registry suggest that stage, principally defined by characteristic appearance and anatomical location of accumulated mass (lipedema.org/staging), tends to increase with the duration of disease. This, combined with data presented on page 6, presents

staging in a way that minimizes comparison to conditions like obesity. This data also adds to previous studies that suggested that the number of nodules increases according to stage [Herbst 2015].

While these observations need to be confirmed in a formal well-designed research study, there are both scientific and policy implications for the findings. A demonstration of Lipedema’s progression, independent of obesity, reinforces Lipedema’s identity as a distinct condition. Without clear definitions of staging, such as those declared in published research, clinical staging is likely to be imprecise and of little policy value.

Beyond treatment and reimbursement policy, new treatments can sometimes receive expedited approval when applied to serious diseases.

In the US, formally designating a condition as serious requires consideration of “[factors such as], day-to-day functioning, or the likelihood that the disease, if left untreated, will progress from a less severe condition to a more serious one.” [21CFR312.300].

DIAGNOSIS AND STAGING

Lipedema affects more than legs and arms

Many areas are affected to lesser degrees

Lipedema-like texture can be found throughout the body, with varying frequency.

While some practitioners are well-trained to distinguish Lipedema from other conditions, patients know their bodies and identified Lipedema-like features at frequencies consistent with medical literature [Herbst 2015]. Though mostly in the upper leg and arm, Lipedema-like texture occurs elsewhere less commonly.

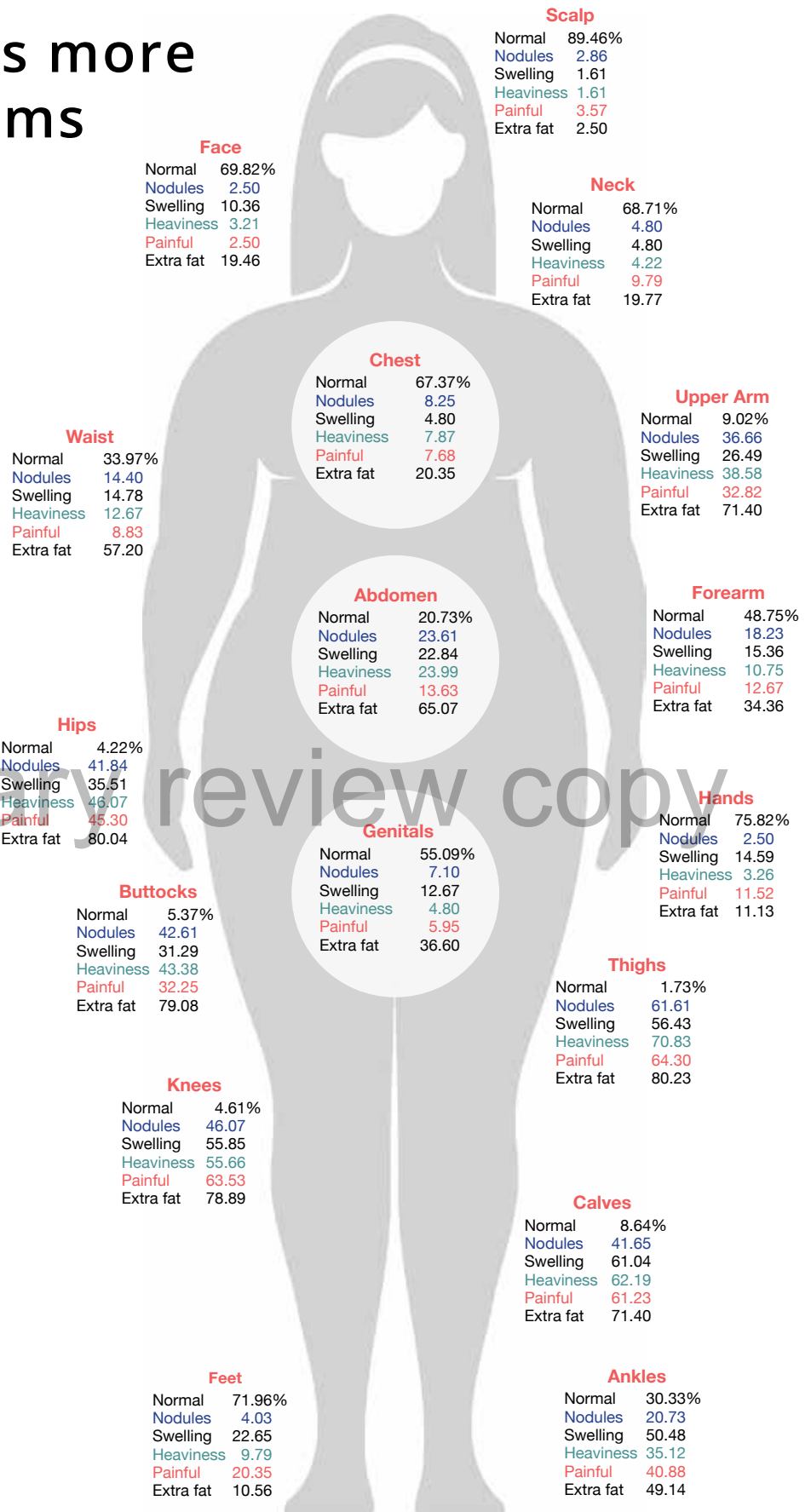
Participants note other symptoms (e.g. pain, swelling, a sensation of heaviness) vary across the body. Focus groups added:

- Heaviness may vary during the day, resulting in a “shuffle” and balance difficulties late in the day.
- Pain may contribute to fatigue, especially when it disrupts sleep.

Fat textures

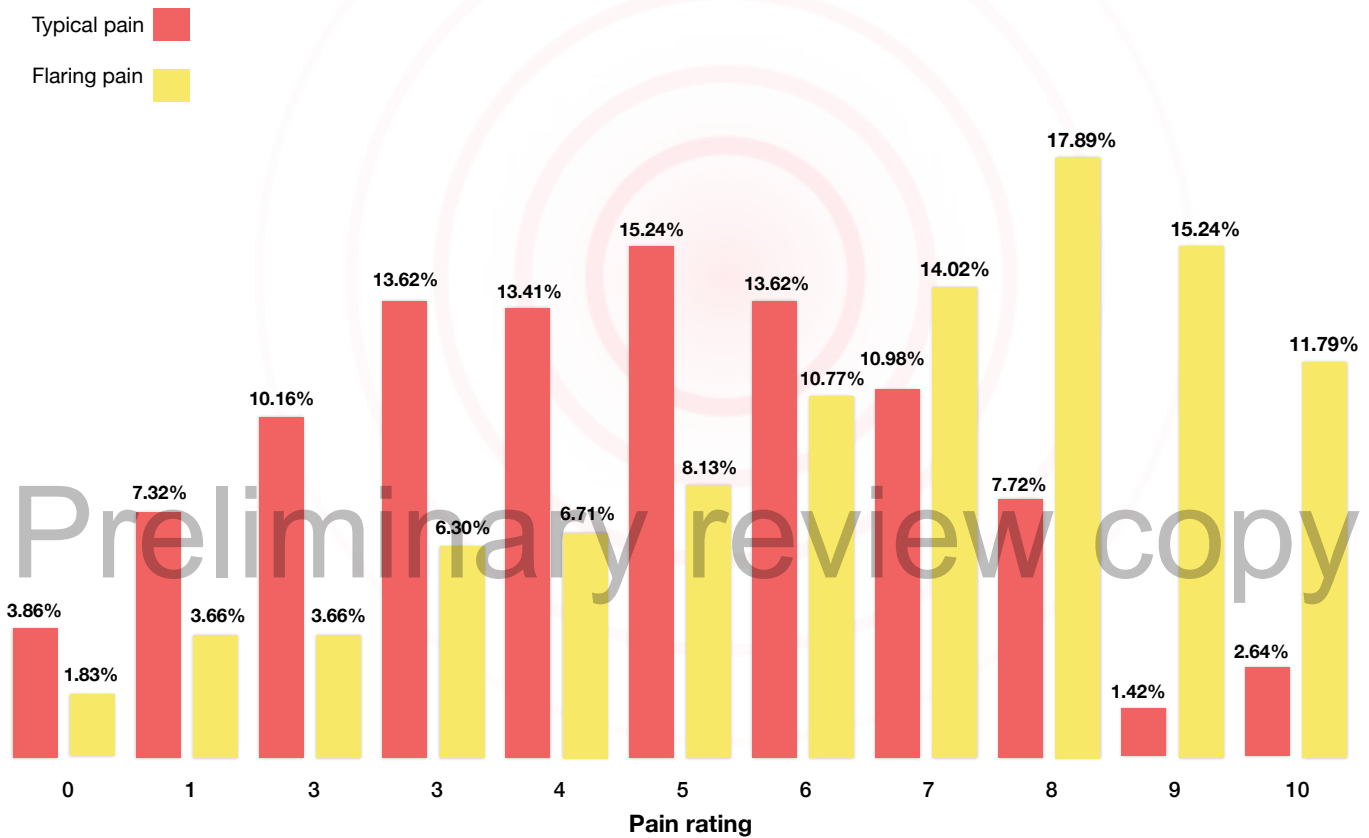
Response to question: “How would you describe how the fat feels in your body?”

	Normal	Rice	Beans	Walnuts
Scalp	90.25	1.36	2.92	0.58
Face	91.72	2.96	1.38	0
Neck	84.25	2.95	3.15	1.77
Chest	74.46	8.45	10.02	1.57
Abdominal	43.42	16.11	23.58	7.27
Waist	53.35	13.58	17.52	4.92
Upper arm	26.04	28.40	28.01	7.89
Forearm	57.87	19.09	10.83	4.13
Hands	91.14	1.97	1.38	0.39
Hips	22.22	17.93	30.41	16.76
Buttocks	18.82	17.65	33.73	17.65
Genitals	69.88	12.99	7.48	0.59
Thighs	8.97	13.26	41.91	26.12
Knees	21.57	18.24	33.14	12.35
Calves	23.74	21.79	27.82	10.51
Ankles	55.29	13.14	11.57	5.49
Feet (toes)	85.12	3.77	2.78	1.19



SYMPTOMS

Life with Lipedema involves consistent pain and flaring



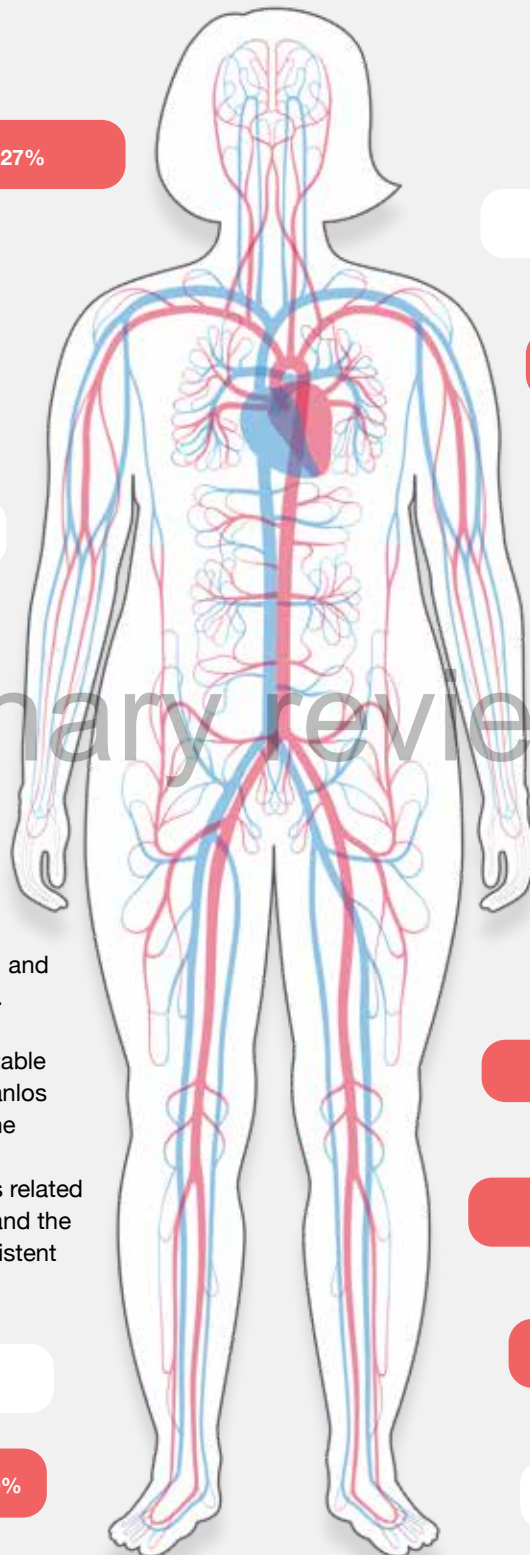
Describing pain in Lipedema

Though not required for the diagnosis of Lipedema by most formal clinical guidelines, pain is nevertheless a hallmark of the condition. The presence of pain, which may come and go in and around affected adipose tissue may be due to inflammation — which would be consistent with periodic flaring. Only 4% of respondents (n=492) reported no pain on a typical day, and average daily pain was five on a 10-point scale, suggesting the average person with Lipedema experiences pain that can be managed but not ignored. Patients report flaring pain at an average of seven, suggesting a level of pain capable of interfering with sleep and other activities.

“ The pain wakes me up all of the time. If you don't enough sleep than anything else you do isn't going to matter a hill of beans. ”
—Focus Group Participant

OTHER CONDITIONS

Immune, vascular, and connective tissue issues often exist with Lipedema



Hypothyroid 27%

HPV infection 16%

Lymphedema 29%

High Blood Pressure 26%

Irritable Bowel Syndrome (IBS) 20%

Anemia 39%

Co-morbidities might be part of the puzzle

By far, obesity represents the most common self-reported condition to exist alongside Lipedema, present in 73% of respondents. Interestingly, diabetes, at 6%, was present at a lower rate than would be expected, given the level of obesity. Patient focus group participants noted that some conditions, such as “pinched nerves”, could vary by body type, and may not appear in aggregate Registry data.

Registry data on common co-morbid conditions, such as spider veins (48%), Irritable Bowel Syndrome-IBS (20%), and Ehlers Danlos Syndrome-Hypermobility (12%), suggest the plausibility of contemporary hypotheses of Lipedema as the consequence of problems related to connective tissue, the immune system, and the vascular system. These findings were consistent after adjustment for age of respondent.

Poly Cystic Ovarian Syndrome 13%

Ehlers Danlos Syndrome-Hypermobility 12%

Knee Problems 54%

Spider Veins 48%

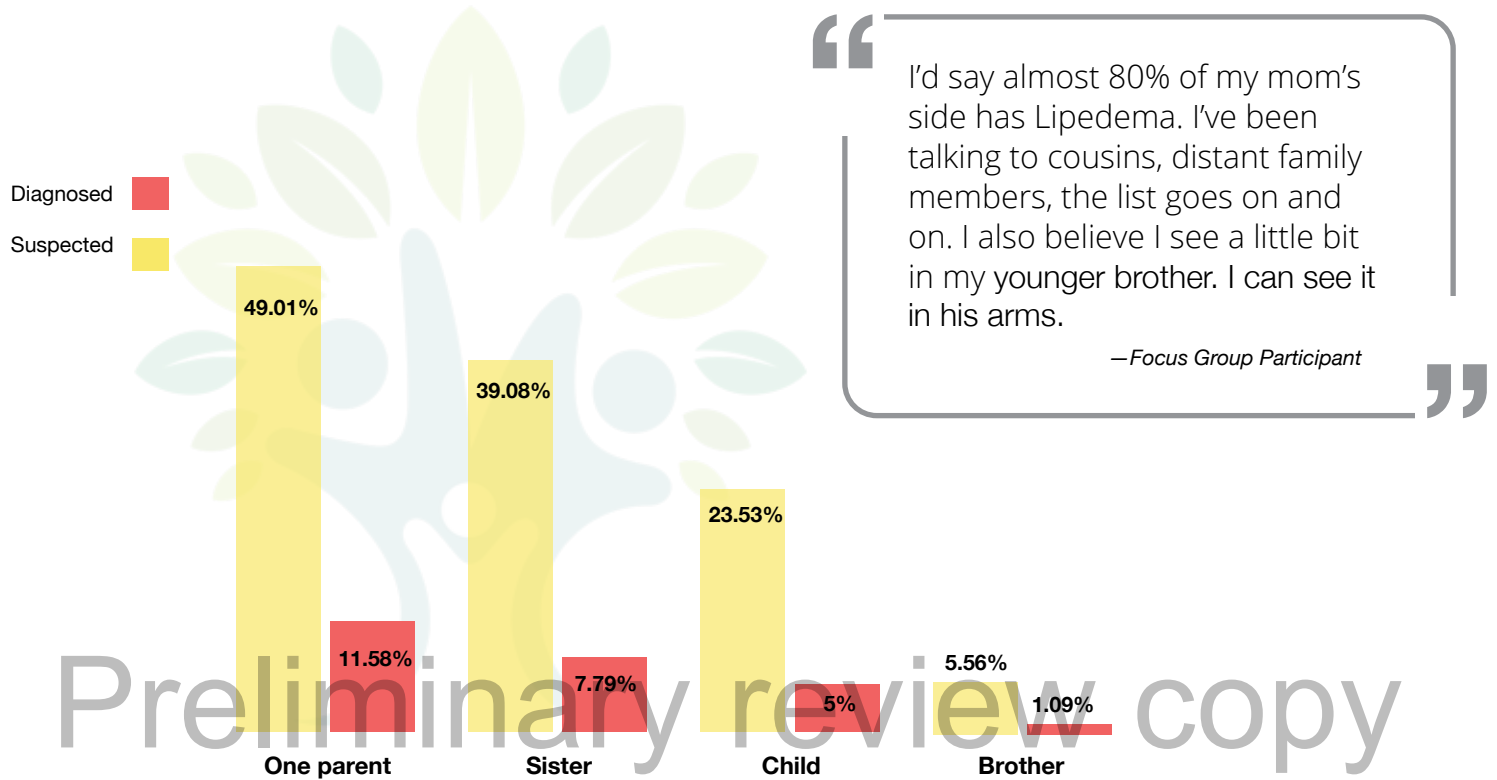
Varicose Veins 38%

Other autoimmune disorders 23%

Flat Feet/Fallen Arches 29%

Venous Insufficiency 19%

Patients likely to have a close relative with Lipedema



“ I’d say almost 80% of my mom’s side has Lipedema. I’ve been talking to cousins, distant family members, the list goes on and on. I also believe I see a little bit in my younger brother. I can see it in his arms.
 — Focus Group Participant ”

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No single gene has been confirmed in medical literature to affect the risk of developing Lipedema

In recent medical studies, patients have reported a family history of Lipedema at high rates, ranging from 64% [Herbst 2012] to 89% [Forner-Cordero 2018]. The likelihood that a woman with Lipedema will have a mother or sister with Lipedema has been estimated at 29-38%, and 5-14%, respectively [Ghods, 2020 and Bauer 2019].

Participants in the Registry were asked to differentiate between immediate family members suspected of having Lipedema and those who have received a formal diagnosis of Lipedema. In all, only 15% of the 521 respondents reported that an immediate family member has been diagnosed with Lipedema, though undiagnosed Lipedema is suspected in 56% of cases overall. The Registry did not ask about grandparents or siblings of parents, while several research studies in the medical literature do include these extended family members. Thus the incidence of patients in the

Registry with a family history of Lipedema is likely in line with the higher ranges reported in the medical literature (~64-89%).

Notably, Registry data reveal that 6-7% of respondents with blood-related male siblings suspect the presence of Lipedema in at least one of those male siblings. This suggests that a well-designed study of family relationships might reveal a greater prevalence of Lipedema-like features in males than previously reported.

Despite a prominent pattern of inheritance, no single gene has been confirmed in the medical literature to significantly affect the risk of developing Lipedema. Thus, Lipedema is likely to be heritable, but by the subtle interactions of many different genes (“polygenic”) rather than determined by one gene (“monogenic”). This speaks to the diversity of ways by which Lipedema may develop, and the need for sophisticated genetic approaches to understand how genetics influences Lipedema.

Bruising, leg heaviness and sensitivity to touch are the most common symptoms

Living with Lipedema

In the Registry data, many of Lipedema’s hallmark symptoms are commonly reported as having occurred in the last 30 days. These include: easy bruising (50% report “very” severe in last 30 days); leg heaviness (65%); sensitivity to touch (42%); and swelling (39%)



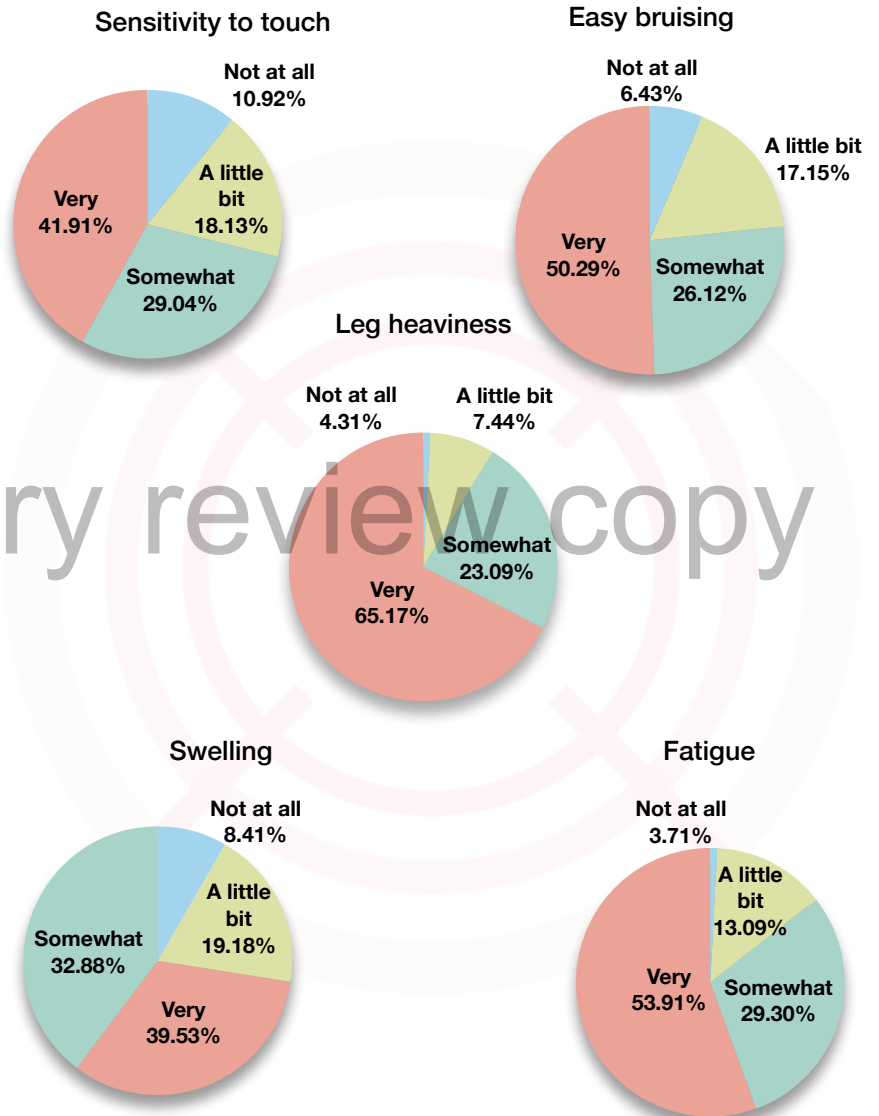
Some symptoms are more variable in response. The perception of severity of **cold legs** is relatively evenly divided between responses reporting no presence in the last 30 days (23%), a little bit (19%), somewhat (27%), and very severe presence (31%). Sleep problems

show a similar pattern.

Some symptoms reported in the Registry warrant further investigation. 83% of respondents reported **somewhat severe to very severe fatigue**, even though currently only one clinical guideline addresses “fatigue in the extremities” [Halk & Damstra 2017]. The degree to which this fatigue is accompanied by a sense of heaviness, numbness, restlessness, leg pain, or other whole body physical or mental fatigue should be more thoroughly explored, both as a possible primary symptom of the condition or as symptoms secondary to other symptoms, such as sleep deficiency.

Similarly, 90% of Registry respondents reported some level of **joint pain** in the last 30 days. Further exploration of the nature of joint pain may offer insight on the degree to which joint pain is influenced by hypermobility, duration of disease, weight or other factors.

Severity of issues:



TREATMENTS

While treatments are used to manage symptoms, no therapy offers a cure

Respondents believe many treatments may work, but access is limited

In general, treatments for Lipedema can include healthy eating programs, weight management, physical activity, compression therapies, and surgical modalities. The Registry asked respondents about the wide selection of possible treatments listed in the accompanying charts; there are other treatments that were not asked about in the Registry. While therapies are used to help manage symptoms and optimize health, no therapy offers a cure.

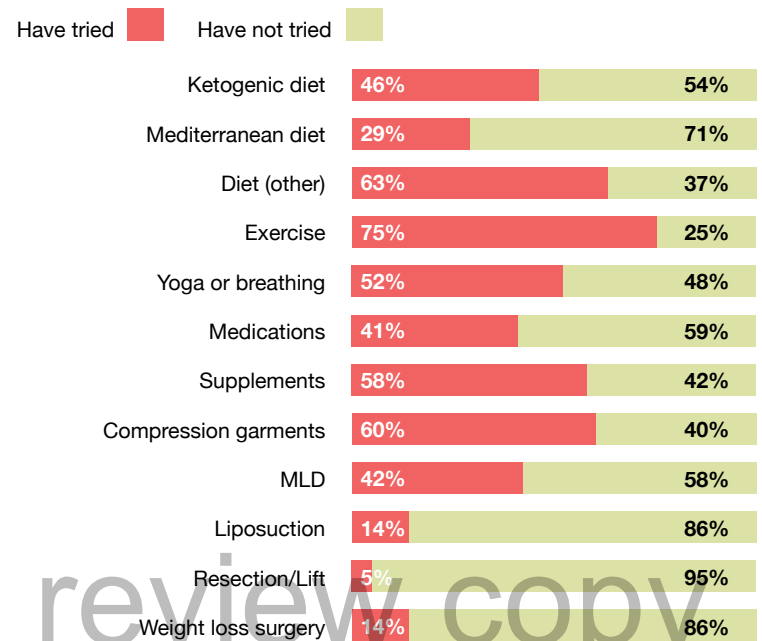
The most tried treatments reported by Registry respondents were those with lower barriers (e.g., cost, prescription, risk, recovery time, need for a prescription) and those that one can try at home. These include exercise (75%), nutritional plans (63%), and compression garments (60%). In addition, more Registry respondents have tried conservative treatments — manual lymphatic drainage (42%), medication (41%), supplements (58%) — than have tried surgical treatments, including liposuction (14%), weight-loss surgery (14%), resection/lift (5%).

In addition to asking which therapies worked, the Registry survey also asked participants to offer their perspective specifically on two difficult-to-treat symptoms: pain and body shape. While all therapies offered some benefit, physical therapy modalities and surgical treatments (liposuction) were the only therapies believed to influence both pain and shape in more than one-third of respondents.

Though the Registry only asked participants specifically about pain and shape, focus group participants noted that benefits are often complex, and a patient may seek out therapies for a variety of reasons beyond just pain and shape. Other symptoms for which patients might try these interventions — not captured in the Registry survey as currently structured — include limited mobility; sleep difficulties; mood; social confidence; other psychosocial benefits; or symptoms derived from co-morbidities. Focus group participants also noted that patients may cycle between therapeutic strategies, as results may not be long lasting or specific regimens may be challenging to maintain.

Unfortunately, access and affordability of many treatments remains a barrier to care. Insurance companies have been slow to recognize much needed Lipedema treatments, and even healthy lifestyle changes (e.g., diet and exercise) can incur significant out-of-pocket costs.

Treatments tried



What helped or didn't help with pain and shape

	(n = 521)	Helped Pain	Helped Shape	Did Not Help
Ketogenic diet	238	25.21%	37.39%	28.99%
Mediterranean diet	150	16.00%	16.00%	37.33%
Diet (other)	329	14.89%	27.05%	34.95%
Exercise	389	23.91%	32.39%	29.05%
Yoga/breathing	273	36.26%	10.99%	29.30%
Medications	211	32.23%	10.43%	34.50%
Supplements	301	18.94%	7.31%	35.55%
Compression garments	310	42.90%	40.65%	24.19%
MLD	221	45.25%	33.03%	23.53%
Liposuction	72	37.50%	65.28%	16.67%
Resection/Lift	24	20.83%	66.67%	8.30%
Weight loss surgery	73	17.81%	35.62%	21.92%

NEXT STEPS

A call to action

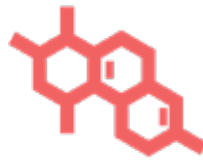


Challenge healthcare professionals to understand Lipedema as a common disorder

We do not yet have clear diagnostic tests for Lipedema, and the full range of effective treatments for Lipedema is unknown. What is clear is that the physical and social burden of Lipedema exists for many years before it is first detected or treated.

Analysis of the Registry responses reminds us that women with Lipedema report their data in a manner that is consistent with the medical literature. Too many are stigmatized or dismissed when they seek care. This data demands their full respect as partners in their care.

The Registry data challenges healthcare professionals and policy makers to educate themselves and each other about the unique features of Lipedema, and the degrees to which strongly held opinions are changing as better evidence becomes increasingly available.



Use data to tell a new story about Lipedema

What it means to have Lipedema can be clouded by how forcefully any one anecdote about living with the condition is projected through social media, friends and family, or the healthcare system.

Data from the Registry provides wider context to powerful individual stories. The data reminds us that Lipedema is not one experience or one community, but many.

Consider sharing this report with healthcare providers that may not be aware of Lipedema, and with patient communities who may not realize that millions of other people share their symptoms.



Inform scientific research

Lipedema research is in a Renaissance, growing in the number of researchers interested in the condition and reports in the medical literature.

The aggregated experiences of women with Lipedema reported here suggest new hypotheses for researchers to explore.

They also challenge researchers to go beyond commonly held beliefs about Lipedema, to carefully investigate issues like the origin and development of the condition and differences that may manifest according to age, race, or co-morbid conditions.

This acceleration of research is vitally needed as we seek to evaluate existing treatments. A future of affordable, accessible, and evidence-based approaches to Lipedema requires understanding not just the causes of the condition, but also the myriad impacts of Lipedema on patient lives.

Expand and diversify Registry participation

Registry participants have taken a brave first step. Their contributions on patient's lives are helping to generate new hypotheses about Lipedema and provide context to current and future studies.

We now need help in expanding and diversifying participation:

- If you identify with a group or demographic that is underrepresented in this data, especially people of color, please contribute to help make the Registry more reflective of the true diversity of the Lipedema population.
- The Registry will be much more valuable if we can compare the data of people with Lipedema to people without the condition. Please help recruit people without Lipedema to complete the survey.
- If you've started the Registry survey but haven't finished it, please complete it so the field can benefit fully from your experiences.

Please let your experience be counted by contributing your data!



My general practice doctor had never even touched my legs – he didn't believe I had Lipedema! But I was right. We know our bodies and with the Registry data we know we're not alone."

—Focus Group Participant



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This bibliography provides a limited number of examples of relevant citations. Due to space constraints, many deserving articles have been omitted. Please visit www.lipedema.org/library for a comprehensive list of Lipedema research studies.

Acknowledgments

The comments and interpretations presented in this document were informed and reviewed by a panel of patient partners including Sharie Fetzer, Linda-Anne Kahn, Isobel MacEwan, Rebecca Morris, Marlene Simpson, Jessica Webb, and Nola Young. The Foundation is deeply indebted to their thoughtful and thorough review of the draft analysis and gratefully acknowledges their contributions.


Preliminary review copy





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