

Learning by Listening

Lipedema Foundation Registry Findings – A First Look



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DISCLOSURES

Nothing to Disclose

The Lipedema Foundation receives no external funding, and sells no products, nor services.

Disclaimer

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Nothing in the Content should be considered, or used as a substitute for, medical advice, diagnosis or treatment.

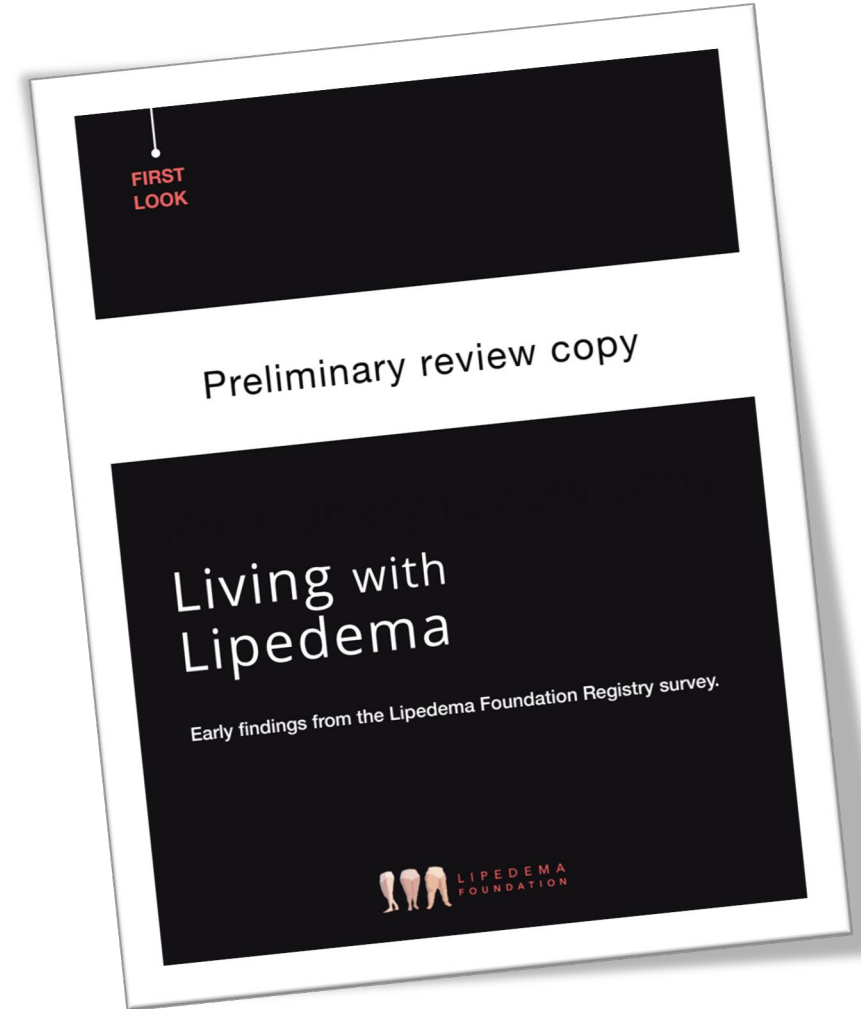
Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.





LF Registry Now Has 2200+ Participants

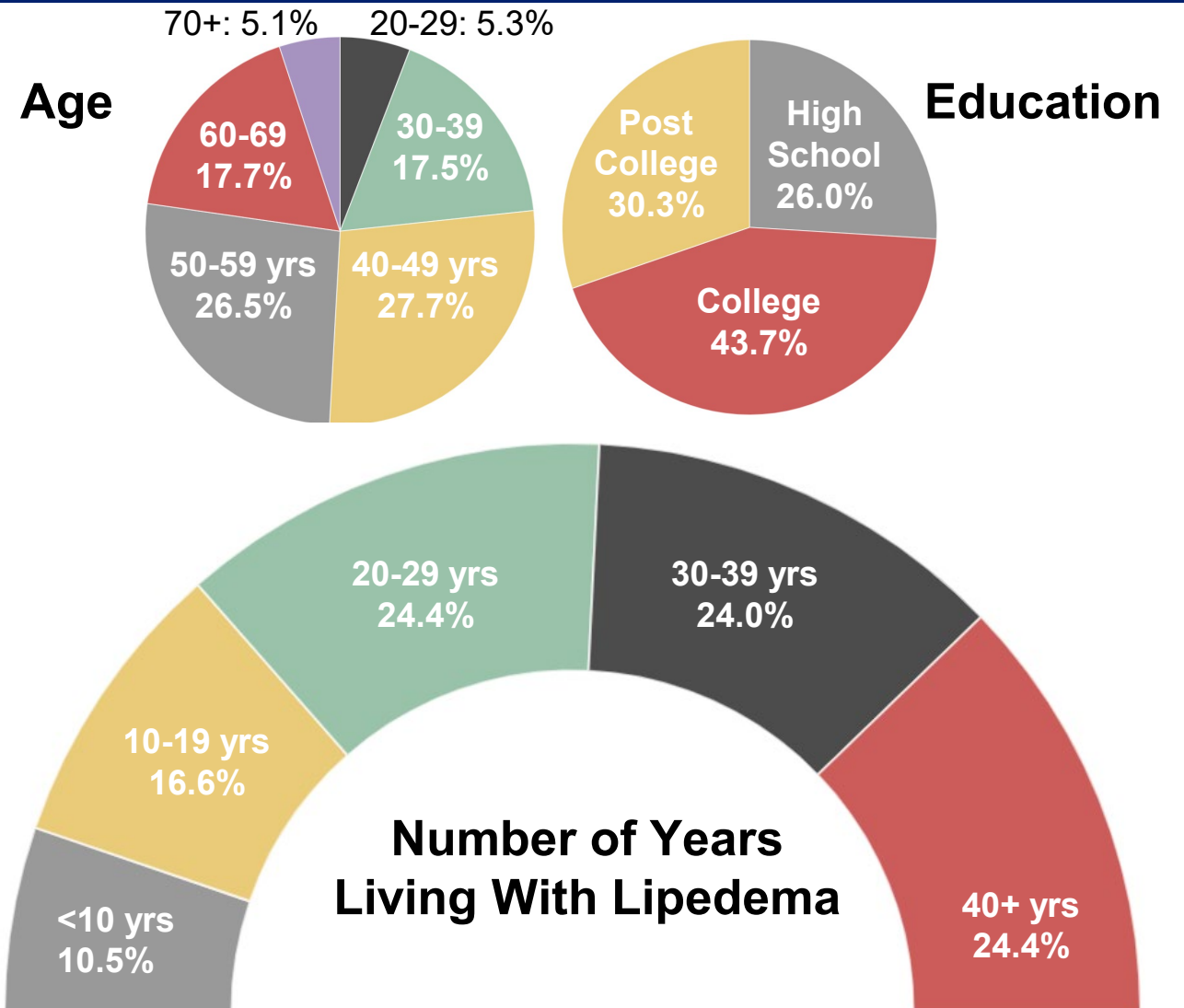
- Launched 2019
- Resource to help those affected by Lipedema and those who care for them better understand and treat Lipedema
- Analysis presented today includes 521 completed survey responses
- This is our view of the findings, plus invaluable interpretation by two focus groups with people with Lipedema





Who participated

- Lipedema crosses age, educational background, body type
- Reflects a community with varying years of experience living with Lipedema
- **14,000+ years** of combined experience living with Lipedema are represented



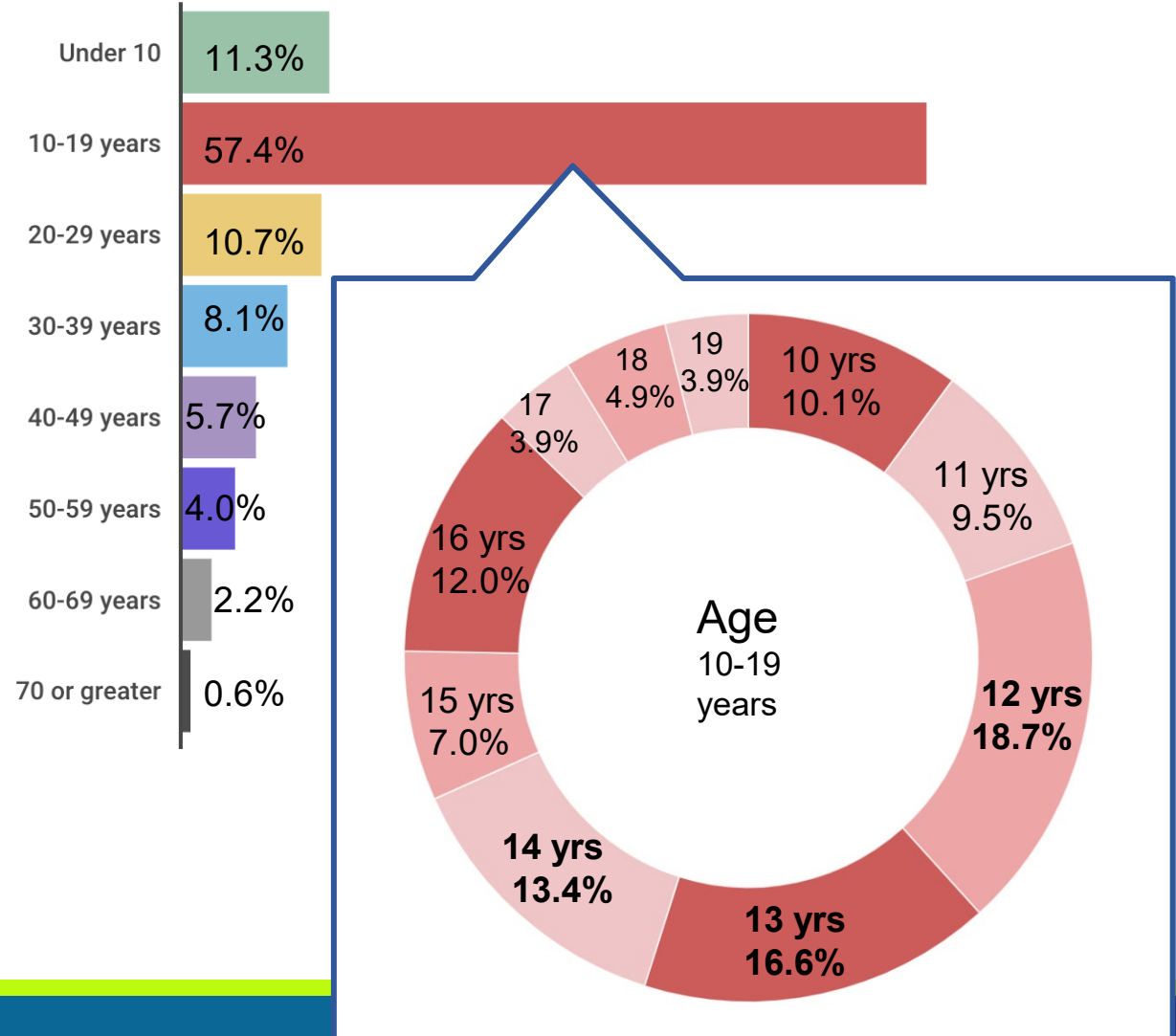


Onset & Diagnosis of Symptoms

- Similar to other research, Lipedema onset often begins during puberty
- Primarily, medical doctors & surgeons are diagnosing Lipedema
- Average age seeking medical help is 39.6 years old

48.1
Average Age
of Diagnosis

Age of Lipedema Onset





Staging – Is Lipedema Progressive?

- Staging seems to correspond with duration of disease
- Focus groups encourage self management at all stages
- Staging definitions focus on texture and nodule sizes

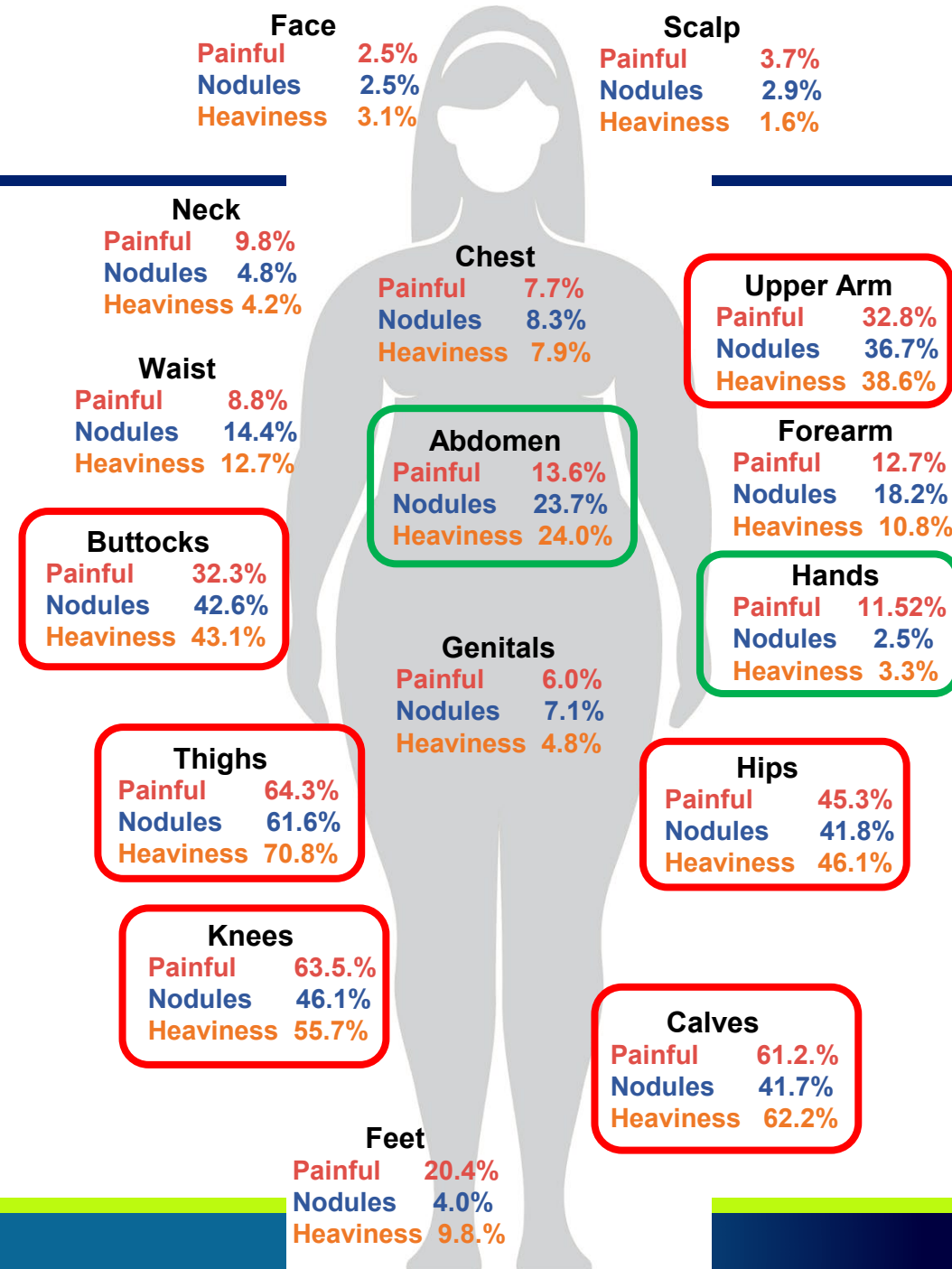
Number of Years Living with Lipedema

	< 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



Lipedema is More Than Legs & Arms

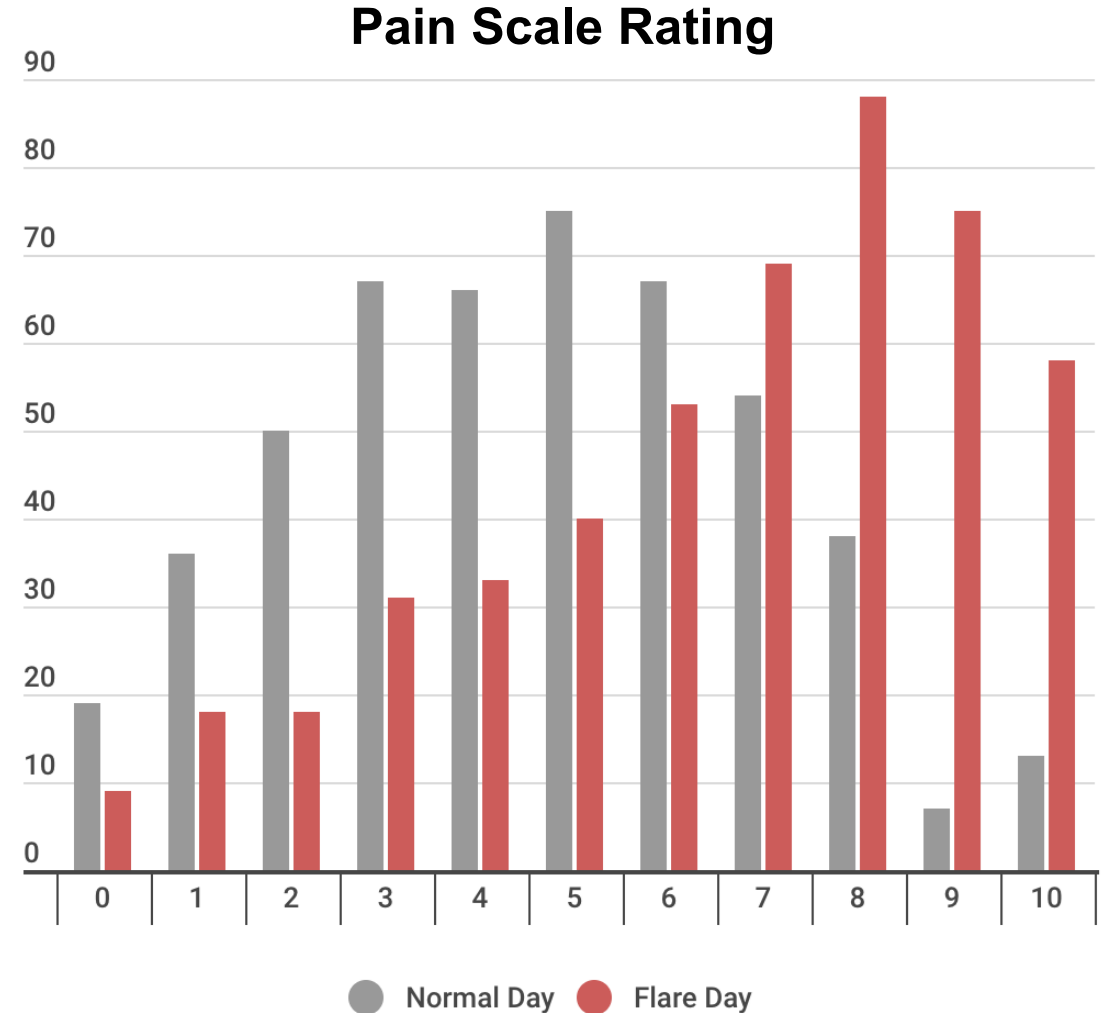
- Symptoms described by body area
- The data women report is consistent with what's in the medical literature
- Highest percentages of typical lipedema symptoms in extremities
 - Includes the affected areas of the lower half of the body, and the arms
- But! Other areas affected
 - Abdomen can be affected and even the hands
 - *Very few clinical guidelines mention nodules as part of their diagnostic criteria*





Pain and comorbidities are common

- Pain is similar to other chronic pain conditions, and can flare significantly
- Common comorbidities are:
 - Spider veins (48%)
 - Venous Insufficiency (19%)
 - Irritable Bowel Syndrome (IBS) (20%)
 - Ehlers-Danlos Syndrome - Hypermobility (12%)
 - Anemia (39%)
 - Knee problems (54%)



...what if it's Lipedema?

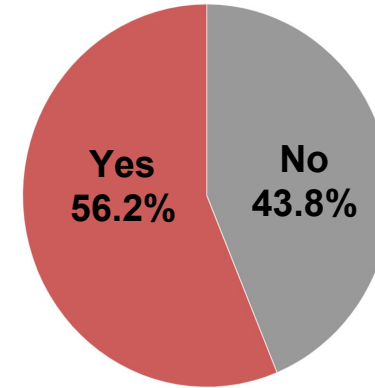


L I P E D E M A
F O U N D A T I O N

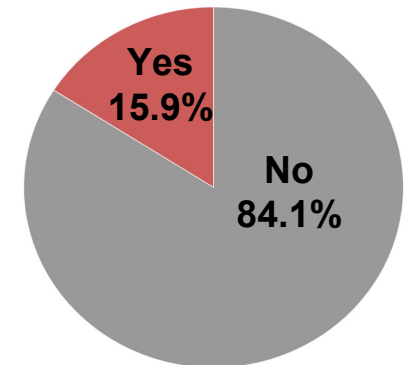


Lipedema tends to run in families

- LFR data are consistent with medical literature, which reports family history in 60-89% range
- LFR goes further to investigate:
 - Suspicion vs diagnosis
 - Male relatives with Lipedema symptoms



Suspected or Diagnosed with Lipedema in the Immediate Family



Diagnosed with Lipedema in the Immediate Family

5.6% Suspect Lipedema in their Brothers



See lipedema.org/blog



L I P E D E M A
F O U N D A T I O N

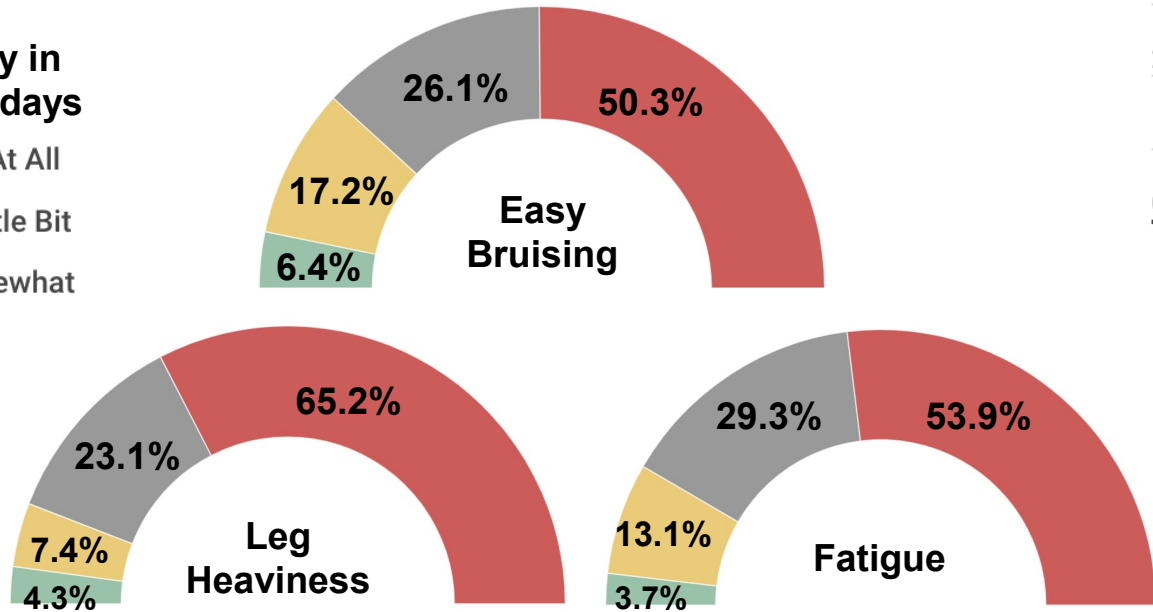


Daily Life

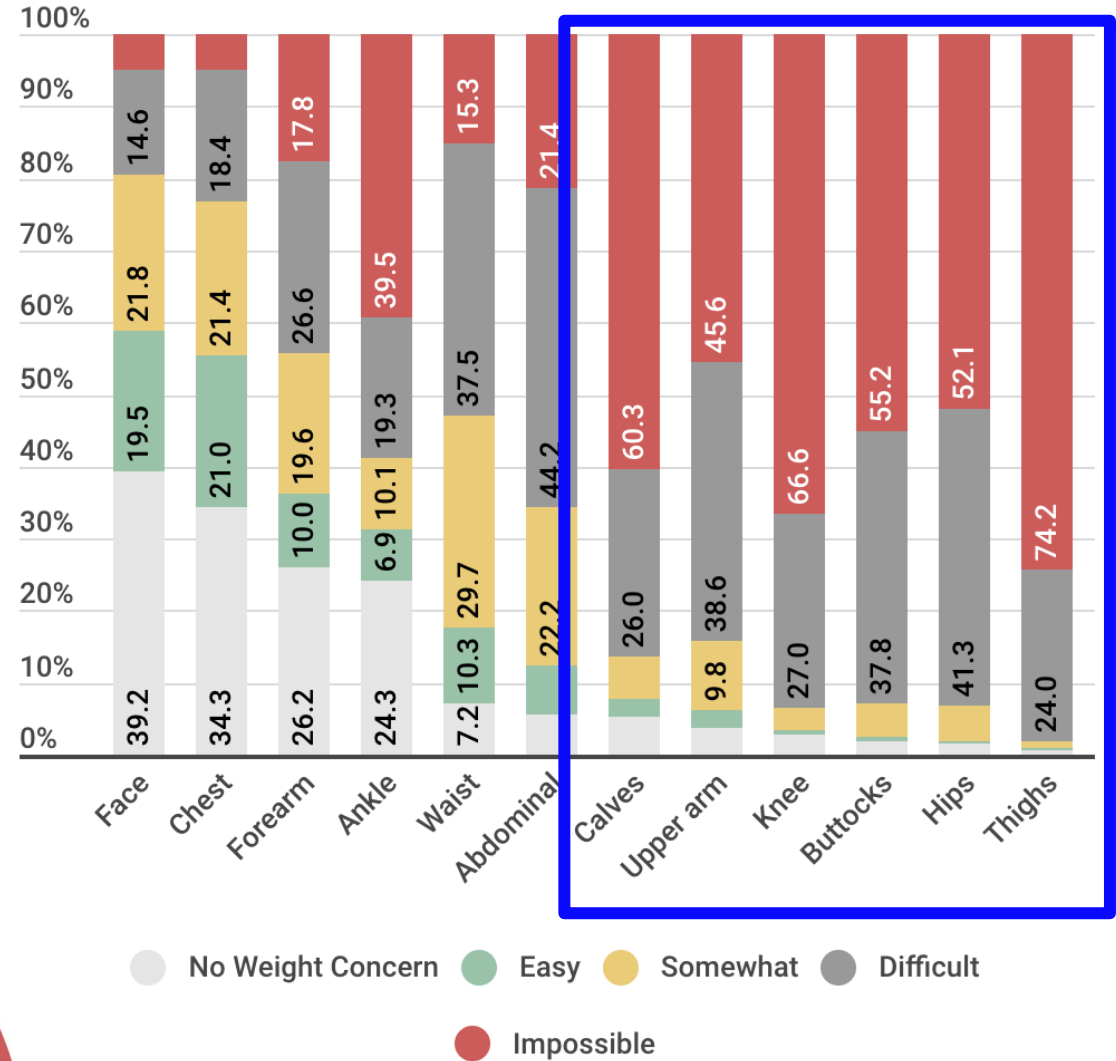
- Easy bruising, sensitivity to touch, leg heaviness, swelling are a fact of daily life
- Other prominent features include fatigue, joint pain, muscle cramping
- Disproportionate weight loss, inability to lose weight from affected areas are reported

Severity in last 30 days

- Not At All
- A Little Bit
- Somewhat
- Very



How difficult is it to lose weight across the body?





Treatments

- Things people can do themselves are the most tried
 - Exercise, nutrition plans, compression
- Conservative therapy options also frequently tried
 - Manual Lymphatic Drainage (MLD), Supplements, Medications
- How did they help?
 - MLD & compression garments reportedly helped pain the most
 - In addition to surgeries, compression garments & ketogenic nutritional plan reportedly were successful in helping shape

	(n)	Helped Pain	Helped Shape	Did Not Help
Ketogenic diet	238	25.2%	37.4%	29.0%
Mediterranean dt	150	16.0%	16.0%	37.3%
Diet (other)	329	14.9%	27.1%	35.0%
Exercise	389	23.9%	32.4%	29.1%
Yoga/breathing	273	36.3%	11.0%	29.3%
Medications	211	32.2%	10.4%	34.5%
Supplements	301	18.9%	7.3%	35.6%
Compression garments	310	42.9%	40.7%	24.2%
MLD	221	45.3%	33.0%	23.5%
Liposuction	72	37.5%	65.3%	16.7%
Resection/Lift	24	20.8%	66.7%	8.3%
Weight loss surgery	73	17.8%	35.6%	21.9%

**** More research is needed ****



This is a “first look” - what’s next?

- Share with us
 - Reactions
 - What else you would want to know
- Complete the survey – and recruit friends
 - Verify that you’ve completed and submitted it by logging in
 - This survey (and Lipedema research) needs more controls
 - We need greater diversity
- Keep advocating
 - Share with your healthcare providers
 - Use this data to amplify your own story



Thank you

Acknowledgements

- All those who have completed the Registry survey
- People with Lipedema and professional advisors who helped make the Registry possible
- First Look report focus group participants
 - Sharie Fetzer, Linda-Anne Kahn, Isobel MacEwan, Rebecca Morris, Marlene Simpson, Jessica Webb and Nola Young

This is your data and report – to help tell your story

An active community creates change

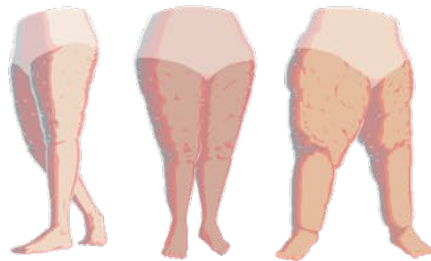


CONTACT INFORMATION

Visit our Booth!

Reach any of our staff by email
info@lipedema.org

Or connect via social media.



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FAT DISORDERS
RESOURCE SOCIETY

FDRS 2022
April 22-24
Intercontinental Hotel Cleveland (at Cleveland Clinic)
Cleveland, OH