Polly Armour

Lipedema Patient and Advocate


OH YOU'RE FROM NEW YORK?
NO. I'M FROM NEW YORK.

Polly Armour
52 years old
Self-diagnosed w/ Lipedema July 2013
Formal diagnosis by Dr Herbst October 2013
Travelled to Germany for Surgery with Dr Stutz January 2014

Brief History of Lipedema Awareness

First described in 1940
Allen & Hines
of the Mayo Clinic
(75+ years ago)

parathyroidism, the less damage will have been done to the patient.

VASCULAR CLINICS. X.
LIPEDEMA OF THE LEGS: A SYNDROME CHARACTERIZED BY FAT LEGS AND ORTHOSTATIC EDEMA

E. V. Allen, M. D., and E. A. Hines, Jr., M. D., Division of Medicine:
We wish to describe a clinical syndrome, lipedema of the legs, which is frequently very distressing. In our experience it affects solely women. The chief complaint is of swelling of the legs and feet which has been present for many years; in some instances, first noted in girlhood. On questioning, the physician may elicit that enlargement of the limbs has always been generalized and symmetrical. Usually, it is associated with gradual increase in body weight. There is never a history of recurrent episodes of acute cellulitis such as may occur in the course of lymphedema. The swelling below the knees is accentuated when patients are on their feet much and in warm weather. Aching distress in the legs is common. In many instances, there is a history of a similar condition in other members of the family. Ordinarily, such patients are very sensitive about the appearance of their limbs; they wear long skirts and stand behind chairs when in the presence of strangers. They avoid swimming. Evidence of neurosis is likely to be found. Occasionally, a patient feels that her large legs have "ruined her life." Many are "ashamed" of their legs.

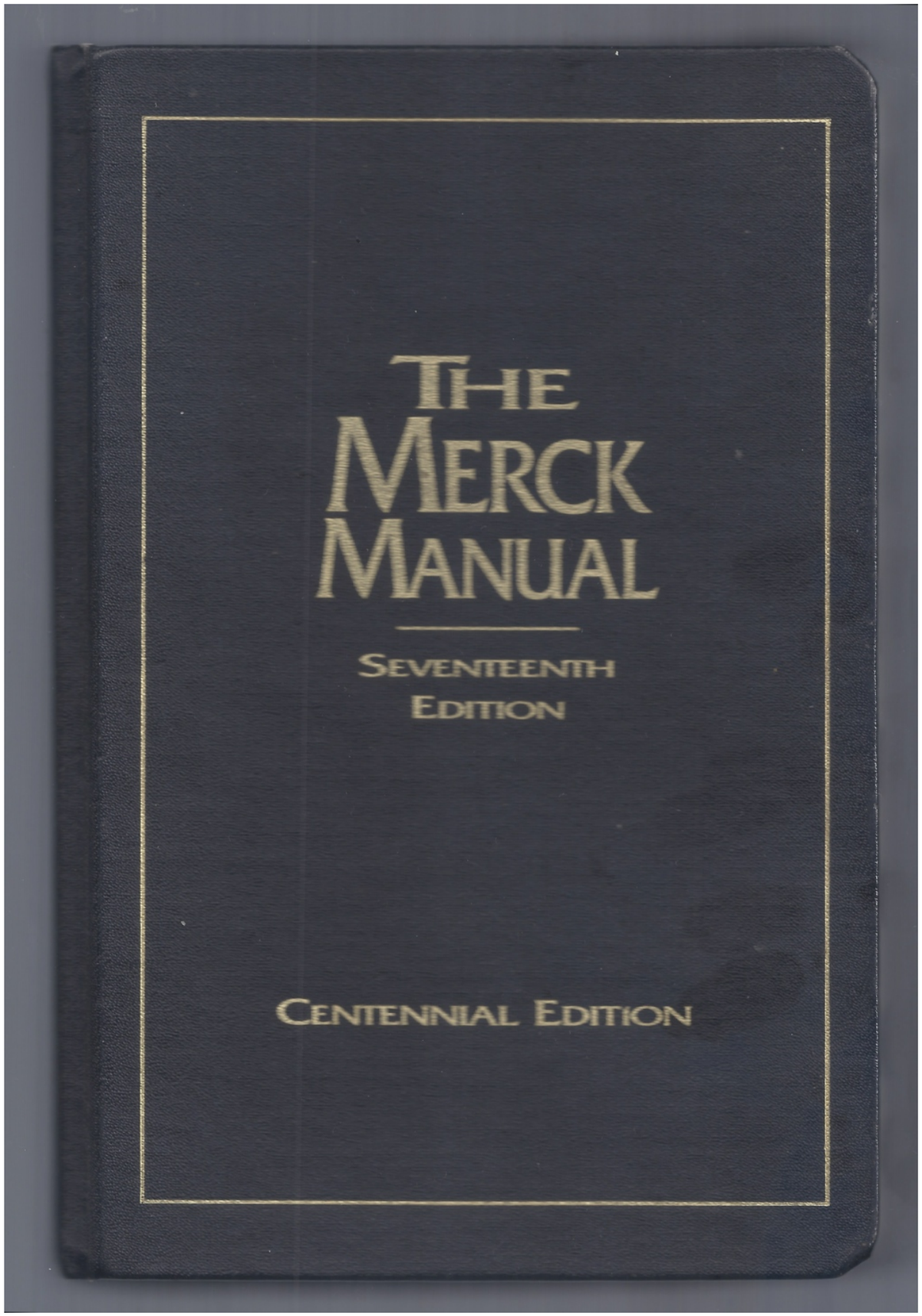
ANATOMIC AND PHYSIOLOGIC BASIS

The basic difficulty in lipedema is the deposition of an unusual amount of fat beneath the skin. An intake of food exceeding the caloric requirements of the body is the obvious cause in cases of generalized obesity. The deposition of fat beneath the skin of the buttocks and legs only, is not easily explained although in many instances it is a hereditary trait. Whatever the basis for increased subcutaneous fat may be, it offers abnormally poor resistance to the passage of fluid into the tissue from the blood and thus permits edema to occur.

Edema is a manifestation of disturbed exchange between the fluid of the blood and that of the tissue. If more fluid than usual leaves blood vessels or if the removal of fluid from the limb is hindered, edema results. Although the transfer of fluid from blood to tissue is primarily controlled by capillary and colloid osmotic pressure, it is greatly influenced by a

Fast forward

60 years



Merck Manual of Diagnosis and Therapy 17th Edition 1999 (18 years ago)

usually small, recompression is not usually required.

ARTERIOVENOUS FISTULA

Abnormal communication between an artery and a vein.

Arteriovenous fistula may be congenital, in which smaller vessels are involved, or acquired due to acute local trauma (eg, a bullet or stab wound) or to erosion of an arterial aneurysm into an accompanying vein. The fistula may cause symptoms and signs of arterial insufficiency (including ulceration due to embolization and ischemia) or of chronic venous insufficiency due to high-pressure arterial flow within the involved veins (eg, peripheral edema, venous varicosities, stasis pigmentation). If the fistula is near the surface, a mass can be felt, and the affected area is usually enlarged and warm with distended and often pulsating superficial veins. A thrill can be palpated over the fistula, and a continuous machinery murmur with accentuation during systole can be heard on auscultation. Altered hemodynamics may cause heart failure if a significant portion of the cardiac output is diverted through the fistula.

Congenital fistulas are managed conservatively unless there are significant complications, such as a shortened leg in a growing child. When necessary, treatment is usually initiated with occlusion of the fistula using radiologic techniques. This may involve the placement of coils or plugs into the feeding points from a catheter placed in an artery. Treatment is seldom completely successful, but complications are often controlled. Acquired fistulas usually have a single large connection and can be effectively treated by surgery.

LYMPHEDEMA

Accumulation of excessive lymph fluid and swelling of subcutaneous tissues due to obstruction, destruction, or hypoplasia of lymph vessels.

Lymphedema may be primary or secondary. **Primary lymphedema** can be present from birth (congenital lymphedema), may occur during puberty (lymphedema praecox), and is less often present later in life (lymphedema tarda). It is more common in women. The patient complains of swelling of the foot, leg, or entire extremity. Lymphedema is usually unilateral and is worse during warm weather, before menstruation, and after prolonged time with the limb in a dependent position. There is usually no discomfort. On examination, the edema is diffuse, causes a typical mound on the dorsum of the foot or hand, and is only partially pitting. There are usually no skin changes or evidence of venous insufficiency.

Secondary lymphedema is often a result of infection, especially dermatophytosis in the foot. In older persons, it may be due to malignant disease in the pelvis or groin and may follow radiotherapy. Lymphedema may be complicated by infection (lymphangitis), which is manifested by chills, high fever, toxicity, and a red, hot, swollen leg. Lymphangitic streaks may be seen in the skin, and lymph nodes in the groin are usually enlarged and tender. These features differentiate lymphangitis from acute thrombophlebitis. Obliteration of lymphatic tissue by excision or radiotherapy is another cause.

When lymphedema is due to infection, the response to antistreptococcal antibiotics is often rapid. Swelling is treated by elevation or pneumatic compression and by application of a firm elastic support to be worn while the patient is ambulatory. Occasionally, diuretics are helpful.

LIPEDEMA

(Painful Fat Syndrome)

A syndrome of fatty, tender legs.

Women are most often affected. The patient complains of swollen and tender tissues. Examination shows most fat distributed in the hips, thighs, and legs. Although the foot is spared, fatty tissue often hangs over the ankles. Tissue tenderness is generalized and not over the course of the veins. The only treatment is avoidance of further weight gain. An obese patient may benefit from weight loss; however, abnormal fat in the lower extremities cannot be mobilized, and weight loss occurs in the trunk, arms, and face.

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Merck 18
2006

TABLE 43–1. FOOT MANIFESTATIONS OF SYSTEMIC DISORDERS

FOOT SYMPTOMS	POSSIBLE CAUSE
Pain at rest (feet elevated), relieved by dependency	End-stage peripheral arterial disease
Cold, red or cyanotic feet	Advanced arterial ischemia
Episodically red, hot, very painful feet	Erythromelalgia—idiopathic (most commonly) or secondary to various medical conditions
Foot pain that becomes severe within seconds or possibly minutes, particularly in patients with atrial fibrillation	Embolic arterial occlusion
Cyanosis of a single toe (blue toe syndrome)	Anticoagulation therapy; thromboembolic disease due to aortic-iliac stenosis, or cholesterol embolization (following coronary artery bypass or catheterization)
Bilateral episodic digital pallor and cyanosis	Raynaud's disease or phenomenon
Bilateral resting peripheral cyanosis	Heart failure, especially if peripheral pulses are palpable
Bilateral permanent painless cyanosis (in a young female)	Acrocyanosis
Bilateral edema	Renal, hepatic, or cardiac disease; drugs (eg, Ca channel blockers)
Unilateral edema	Deep vein thrombosis; lymphatic obstruction
Firm non-pitting foot and leg edema	Lymphedema
Firm edema, usually pitting, of the leg only	Lipedema, due to fat and fluid
Firm non-pitting edema with nodular appearance above the malleoli	Pretibial myxedema
Edema with hemosiderin deposition and brownish discoloration	Venous insufficiency
Edema of feet and toes, numbness and pain at the ankle and heel (tarsal tunnel syndrome), cold feet	Hypothyroidism; relapsing symmetric seronegative synovitis (rare)
Red, dusky patches on the dorsum with flaccid bullae (necrolytic acral erythema)	Hepatitis C
Isolated toe swelling and deformity with pain (sausage digits)	Psoriatic arthritis; reactive arthritis
Painful feet with paresthesias	Peripheral neuropathy (local or systemic—eg, diabetic neuropathy)
Pain or paresthesias in the heel; pain in the foot when the leg is extended, relieved when the knee is flexed	Sciatica
Toe or ankle pain with warmth and redness	Gout
Painful ambulation after rest (post-static dyskinesia)	Arthritis
Thickened (> 22 mm) heel pad	Hyperpituitarism with acromegaly

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- Remove quotes around phrases to search for each word individually. *b*
- Consider loosening your query with *OR*. *bike OR shed* will often show

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1 March 2013

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ASSOCIATION MÉDICALE CANADIENNE
CANADIAN MEDICAL ASSOCIATION

Canadian Dermatology Association
Association canadienne de dermatologie
CDA-ACD

L'ASSOCIATION CANADIENNE des MEDECINS et CHIRURGIENS BARIATRIQUE
The CANADIAN ASSOCIATION of BARIATRIC PHYSICIANS and SURGEONS

CSVS
Canadian Society for Vascular Surgery

No surprise that no one knows about it!

(more on this later)

Considering Liposuction?

- It is NOT the Brand Name of the Gizmo that matters
- It is the **skill of the hand that holds it**!

Most Important Factor:

- Your level of comfort with the surgeon
  - Liposuction is not a drive-thru procedure
  - It is beginning of relationship that will last many months, and require a surprising level of intimacy.

Considering Liposuction?
It is imperative that you
Have Reasonable Expectations

paraphrasing Dr Klein:

Don't expect your surgeon to give you **PREDICTIONS**
(shrinkage, cosmetic improvement, etc)

Instead, work with them to set **GOALS**
(pain relief, mobility, other symptomatic improvement)

Will you be satisfied with a 50% improvement?
If yes, then you are a good candidate

The **average** patient gets significant improvement, but each of us is an individual, not an average!
Your Mileage May WILL Vary

Remember: a Goal is NOT a Guarantee.

Liposuction CANS

Liposuction for Lipedema CAN:

- **Relieve Pain** and other symptoms caused by lipedema
- **Improve Mobility** affected by disordered gait
- **Prevent Progression** to later stages (or at least slow it down considerably).

Liposuction IS'NT/DOESN'T/WON'T:

- a method for weight loss (although many lose weight afterwards)

- a cosmetic procedure (although most do get smaller, and look "better")

- a time machine (although you may feel younger, it will not return lost youth)

- cure other problems/conditions such as RA or MS (it can make them easier to deal with)

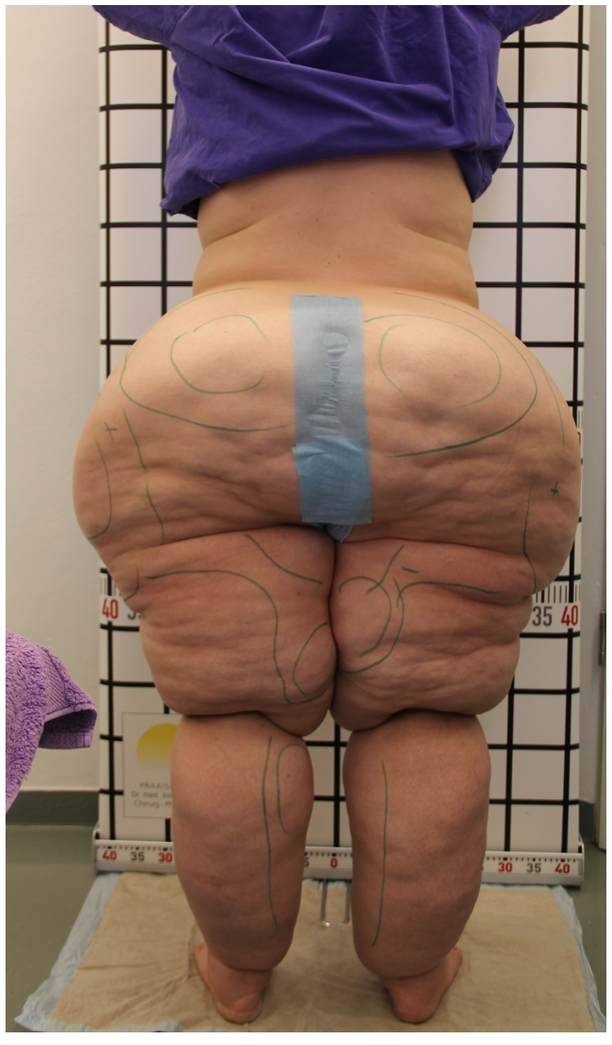
- change other people (your boss will still be a jerk; your 13-year old will still be thirteen, at least for now)

Remember:
LIPEDEMA IS A WHOLE LOT MORE THAN A COSMETIC DISORDER

It needs more than a cosmetic approach to treatment

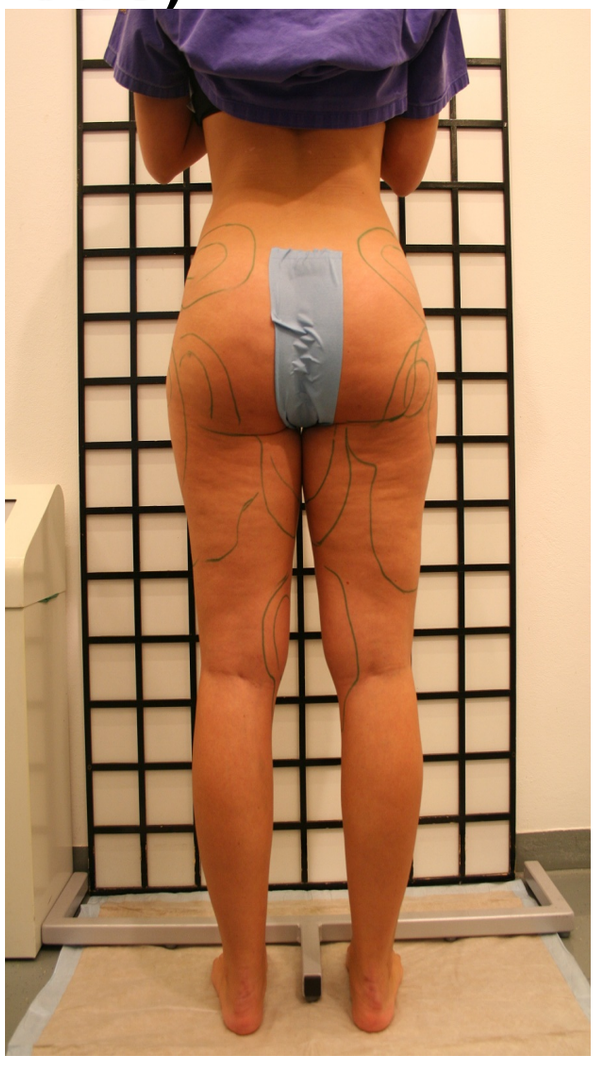
Avoid Emotional Pitfalls

- Don't compare yourself to others (or at least try not to)
- It's not a competition (though it can feel like one)



Q: Which patient will have more liters of fat removed?

A: That is a meaningless comparison!



Before and After Pix?

- Other people's pictures don't tell your story
- Pictures in general don't tell any story!

Photo of an ad on the NYC subway

Before and After Pix?

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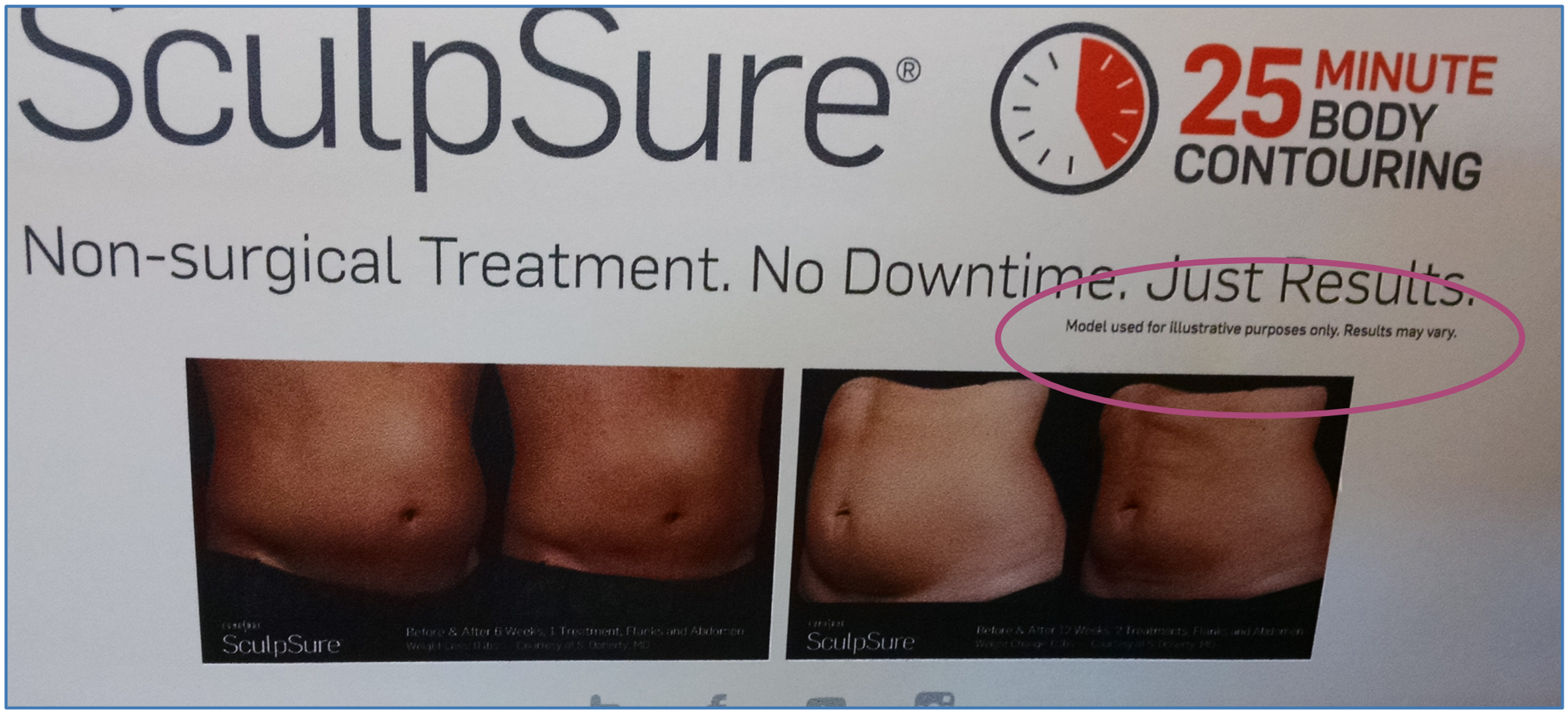
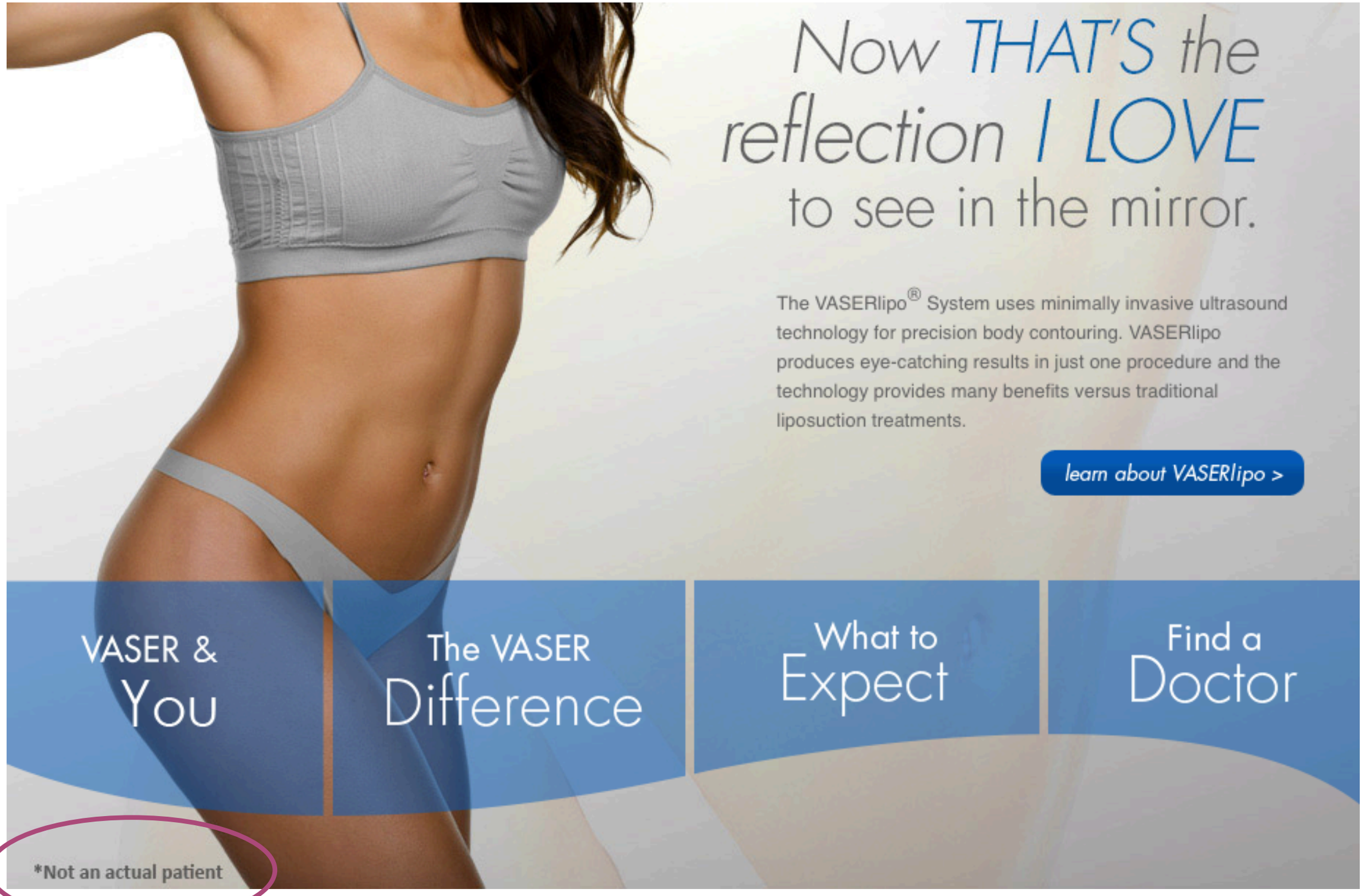
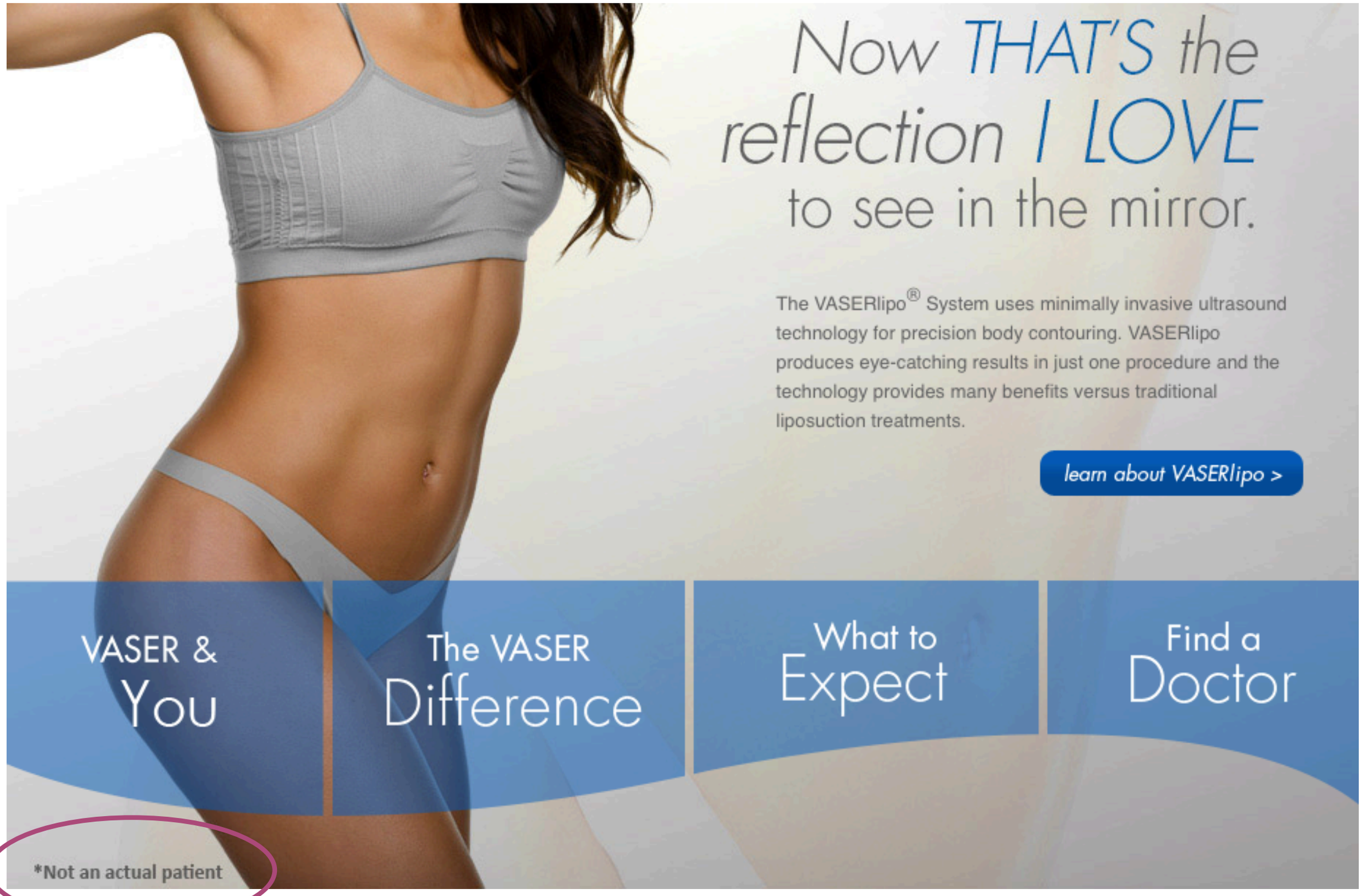


"Model used for illustrative purposes only. Results may vary."



Screenshot from www.vaser.com



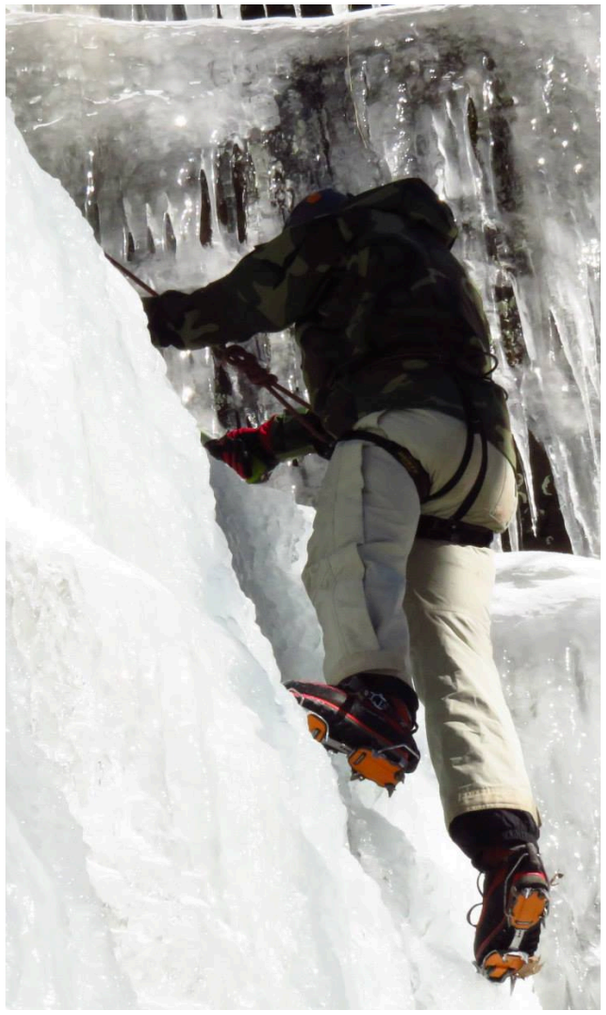
"Not an actual patient"

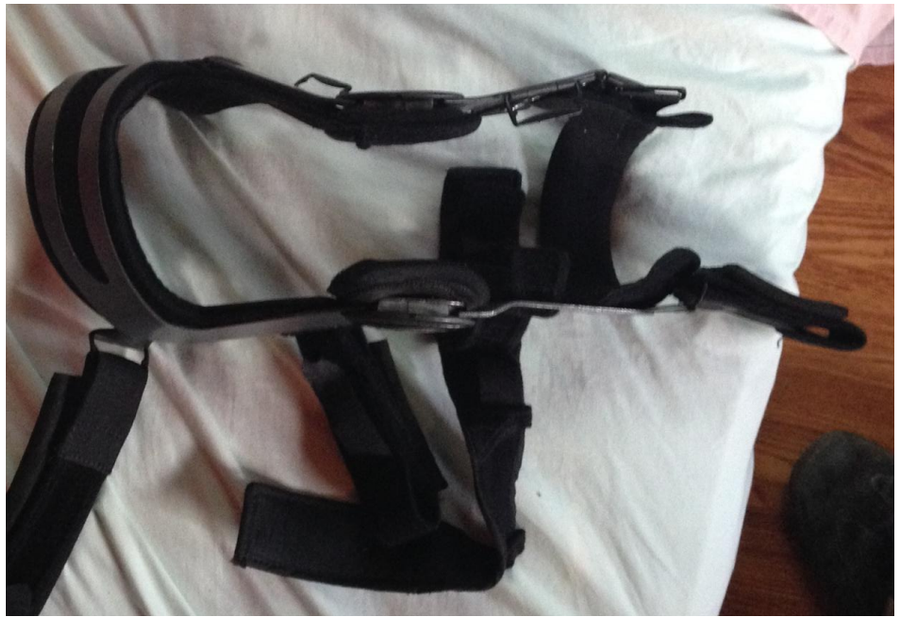
Screenshot from www.vaser.com

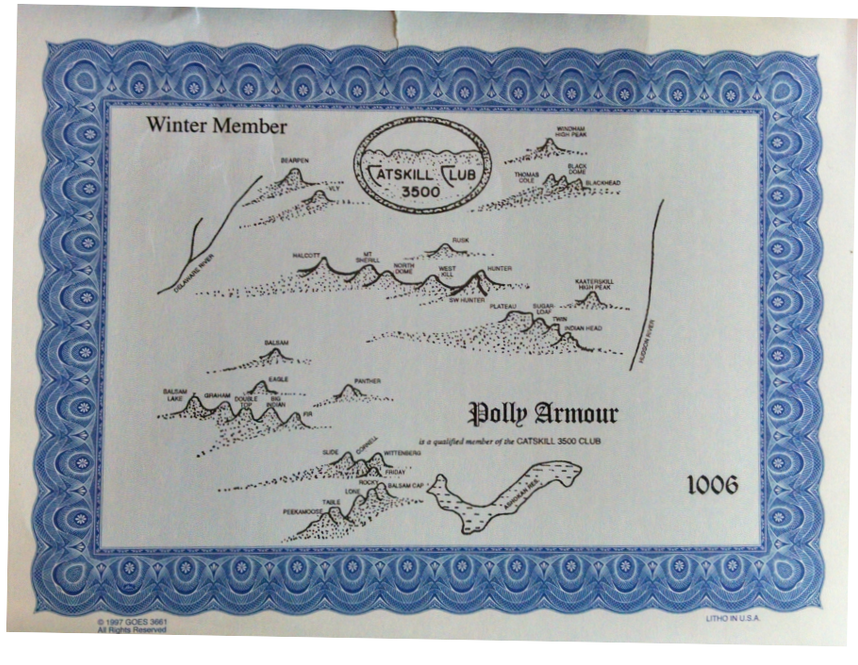
Q: What's the alternative?

A: Remember your **GOALS** and Focus on your "**NMVs.**"

My Non Mirror Victories







Some Last Words

- Be gentle on yourself. Remember how far you've come, and what you accomplished to get there.

- Check in with friends and family for "Independent Verification." They will notice the changes more easily than you will.

- Pay it forward. We're support groups; we must give support as well as receive it. This will help you frame your own experience in a larger context.

Q: What Next?

(What's the difference between Ignorance and Stupidity?)

Q: What Next?

Cure Ignorance!

“My dream doctor would be someone who at least:
- listens and believes that I am telling the truth about my condition,
- doesn't constantly harp about things that are out of my control,
- is hungry to learn all they can to try to help,
- and will go to bat with insurance etc.”

“Tall orders I know."

- R.C., lipedema patient

More Info:

Karen Herbst, MD, PhD
lipomadoc.org

Fat Disorders Research Society (FDRS)
fatdisorders.org

Lipedema Project
lipedemaproject.org

Thank you very much for your time and attention!

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