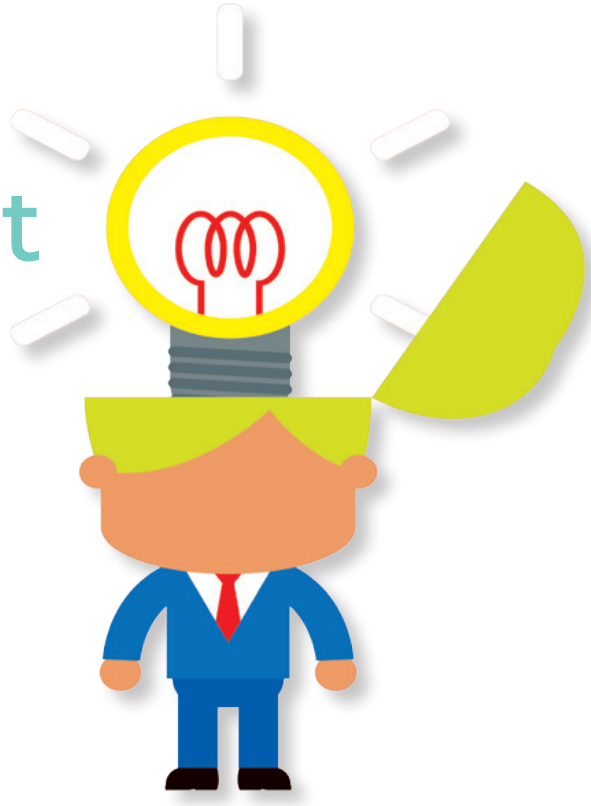
# Lipedema – A new paradigm shift

## An interview with Dr. Tobias Bertsch

In discussion with Anna Kennedy and Pamela Hodgson



**Q How would you define lipedema today?**

According to the European Lipedema Consensus, two main criteria define lipedema: the first is the disproportional fat distribution of the legs (and sometimes of the arms), and the second is the complaints arising from this fat tissue like pain, heaviness, tenderness—that are essential for the diagnosis of lipedema. In other words; to diagnose lipedema, it is not enough if the patient is just suffering from bigger legs.

Women's legs are a tricky topic. It's a tricky issue. I see far more women that come with a diagnosis of lipedema from their doctor. Yet when I examine them, their legs are completely healthy, even though they might not have what society considers as "top model legs". Lipedema is not only big legs, otherwise every woman who is not happy with her legs would say that she has lipedema, and as a consequence want to have Manual Lymphatic Drainage (MLD) or liposuction (at least this is the situation in many European countries where MLD is paid for).

At my lipedema lecture at the 2018 International Lymphoedema conference in Rotterdam, there were around 300 women—mainly doctors and therapists (no patients). I asked the audience "Who among you is happy with your legs?" I saw only five hand signals from approximately 300. That speaks volumes. For this reason, we need the second criterion, the complaints. The other issues the huge majority of patients with lipedema are suffering from and that the European lipedema expert group felt were essential were: weight gain and obesity, and psychological issues. Both criterion have to be considered in regards to proper diagnosis and therapy of the patients.

**Q Tell us how the European Lipedema Forum came to be. Who are the key players and what was the process of consensus?**

In the last few years, the number of lipedema patients was increasing notably. They came into the out-patient clinic and told me their legs are swollen, that they suffer from edema; that they gain weight because of lipedema. At the same time, patients were focused on getting MLD (which is covered by insurance in Germany) and more and more they were focused on liposuction. From my perspective, patients suffered first and foremost from pain in the soft tissue and weight gain as well as mental challenges, like eating disorders, depression, and chronic stress. They suffered from a lack of self-acceptance because of the current beauty ideal in society. So I started to challenge the traditional view of lipedema. I started to lecture about this topic in 2014 and also started to write in 2018 the series of articles "Lipedema; myths and facts", together with my wonderful colleague, psychologist Gabriele Erbacher. I had positive feedback from many medical doctors. However, there was also negative feedback, particularly from doctors who perform liposuction and from patient support groups, who were not happy that I was challenging MLD and liposuction as helpful therapies for lipedema. As a consequence, I invited European experts (Kristiana Gordon, Denise Hardy, Robert Damstra, Ad Hendrickx, Christine Moffatt, Tobias Hirsch, and many other European recognized experts in this field) to discuss the topic of lipedema in a forum. The first meeting was in 2018 and the second in 2019.

> I started to challenge the traditional view of lipedema, lecturing and writing about the myths and facts.

Those invited had either written about lipedema or were on commissions with organized guidelines within their country or were on the board of a society. All of them were treating lipedema patients on a regular basis—that was essential. We used the Open Space concept, suggested by Christine Moffatt, with a professional moderator team leading

**Dr. Tobias Bertsch** is a senior consultant at the Foeldi Clinic in Hinterzarten, Germany, specializing in lymphology and bariatric medicine. In 2008, Dr. Bertsch developed a unique, multi-disciplinary therapy program for patients with morbid obesity, obesity-associated lymphedema, and lipedema. Dr. Bertsch is the leading author of the article series *"Lipoedema - myths and facts."* He organized the European Lipoedema Forum that created a Consensus and Best Practice Document on Lipoedema, published in 2020.

the meetings. The result was the European Consensus, which is published in part 5 of the article series about lipedema (see references).

**Q Can you help us understand what the key myths are and how they have been challenged by your group?**

**MYTH 1: Lipedema is a progressive disorder.**

Its obesity and weight gain that is progressive. Many patients come scared that lipedema is progressive. They see pictures of severely obese women and they read a lot of misinformation from some lipedema websites. As a result, they are afraid they will end up like many of these obese women. In actual fact at the Foeldi Clinic, every day we see patients with lipedema who present a completely stable lipedema over many years because their weight remains stable. Every patient at the Foeldi clinic gets weighed and measurements are taken of the stomach and legs. We have measurements spanning 20 years and we see these patients are completely stable.

Isabel Forner-Cordero from Spain, conducted a study, which she presented last year at the International Society of Lymphology (ISL) in Buenos Aires. All patients in her study who could stabilize their weight could also stabilize the volume of their legs. Only those who gained weight experienced an increase in their leg volumes. By the way, there is no pathophysiology, no scientific concept, which could explain why, and how lipedema should be progressive. Not at all. This is really good news for our patients; they should know that lipedema is not progressive, that lipedema will be stable—if their weight remains stable.

**MYTH 2: Lipedema causes mental illness.**

The psychologist at the Foeldi clinic published two studies, the last one, published in September 2020 followed 150 patients[1,2]. According to these studies 80% of lipedema patients suffered from mental issues like eating disorders, post-traumatic-stress-disorder, depression, chronic stress, burnout and others. The huge majority of them had these mental problems before the lipedema problems started. This is essential to understand, because something that precedes the development of lipedema cannot be its cause. We have consistent data that shows the impact of psychological issues and of chronic stress on pain perception. This is highly relevant for patients with lipedema.


But in addition to these mental problems, there is also social pressure because of the current beauty ideal. I love the Spring *Pathways*, as 99.9% of magazine covers show very slim women with very slim legs. There are girls and women who believe if their legs don't look like these, they may have lipedema.

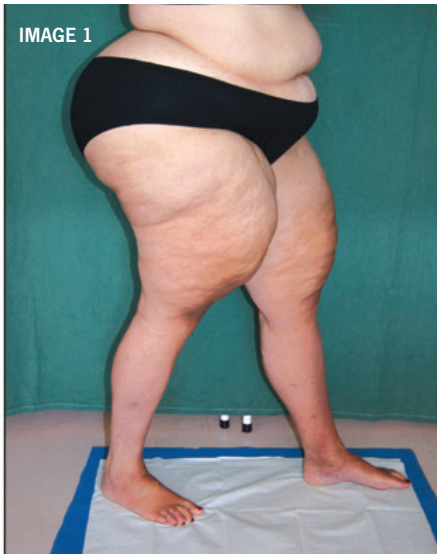
**MYTH 3: Lipedema is primarily an edema problem and MLD is an essential treatment.**

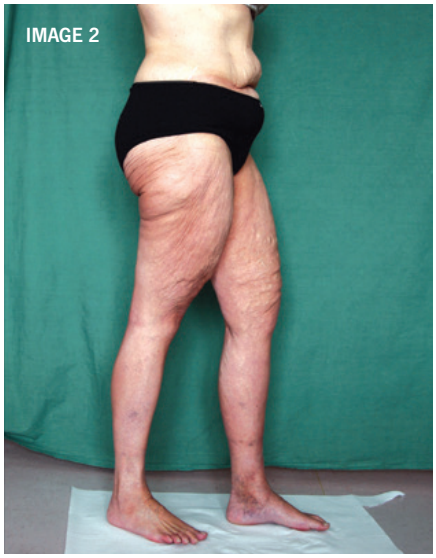
I would say this is the key myth because the name 'lip-edema' suggests that there is edema, for which the treatment—at least in Germany, Europe, and many countries—is MLD and decongestion. But if there is no edema, you don't need decongestion. Research from the 1940s that first mentioned lipedema states that only 20% of them had mild edema in the evening, or maybe in the hot summer months following prolonged standing. Many traditional experts say that lipedema is an edema disease and edema is the cause of the pain. But that makes no sense because then all patients with severe lymphedema would have pain too. And we know that is not the case.

No imaging techniques like CT, MRI, and high-resolution sonography have ever brought evidence for edema in patients with lipedema. Never. A multicenter study led by Tobias Hirsch[3], who also is a member of the European lipedema expert group, using high-resolution ultrasonography, concluded that there is no fluid in lipedema patients. When we have no fluid we have no edema and when we have no edema we need no decongestion.

**MYTH 4: Lipedema makes you fat.**

There is a strong stigmatization and "fat-shaming" of obesity in society. For many severely obese people, it is a horrible situation. They get blamed for being obese. Yet obesity is a disease that has many complex causes. Particularly women experience stigmatization and discrimination because of their weight or body shape. This is an important reason why lipedema became much more popular in the last years. "I am not fat, I have lipedema", is a credo for many patient and support groups that you will find on websites[4]. But there is no scientific evidence for this. Nor is there any pathophysiological concept for why lipedema should increase weight gain. Indeed, the opposite seems to be true. Weight gain and obesity is an essential trigger to get lipedema. At the Foeldi Clinic, more than 80% of patients with lipedema are obese. Other centres in Europe report similar numbers[5,6,7,8].




**Before bariatric surgery (left), and after bariatric surgery (right). Lipedema in remission (patient free of complaints).**

**MYTH 5: Weight loss has no effect on lipedema.**

What is the pathophysiological concept behind this statement? When you lose weight why should you lose weight everywhere but not in the legs? We see many patients who lose weight (after bariatric surgery) in the legs because we take the measurements[7,8] (refer to images on page 6).

**MYTH 6: Liposuction leads to a marked and persistent improvement in lipedema.**

With Dr. Nestor Torio-Padron, a professor and plastic surgeon from the University of Freiburg, we reviewed all the data and found that it is not only poor, but also all the data are provided by the doctors themselves who do the liposuction. Therefore we do not have any independent data.

I think a small group of patients may benefit from liposuction, e.g. those not severely obese, with a BMI of 30, with stable weight for many years and with no severe untreated psychological problems. If conservative therapy isn't helpful (compression, exercise, weight management, and sometimes additional psycho-social therapy) these patients may benefit from liposuction. But liposuction makes no sense when they are severely obese, when they have eating disorders, when they are experiencing the yo-yo weight effect.

**Q How do you think that your work and the consensus report will change the paradigm going forward?**

I think that this European Lipedema Forum was a huge step that prompted many other initiatives. Dr. Hakan Brorson from Sweden incorporated the European Consensus and the article series on to the Swedish Lymphology Website. Together with the Dutch group, we are working on a fact sheet with Consensus results, which will be distributed in other European countries as well. A new website for professionals and patients will provide credible evidence-based information about lipedema. It is essential that patients receive information, which is "scientifically-based" and not "interest-based".

Prof. E. Foeldi, who wrote the original textbook on lipedema, has now changed her view and I'm very grateful for that. Many more important and credible opinion experts from 10 European countries support this new view.

I think a lot has happened in this short time frame. We are especially pleased that all the articles we published have been in the Top 10 rankings and are being read by a lot of people. I hope your readers will learn from these articles as well. LP

A full set of references can be found at **www.lymphedemapathways.ca**

**Editor's Note:**
A summary and update of the article series is published as a supplement in the *Journal of Wound Care* (October 2020). Prof. Hugo Partsch, the world-renowned phebologist, wrote the foreword for this supplement.