

## Report Lipedema World Congress Rome 5 – 8 Novembre 2025



In a Rome that seemed almost distracted, or perhaps incredulous, on 5 November, in Pavilion 10 of the Nuova Fiera di Roma, the World Congress on Lipedema, sponsored by the Lipedema World Alliance, kicked off in the morning with a pre-congress session dedicated to surgery. In the presence of over 250 participants, there were various presentations by some of the world's leading experts in the field (Mojtaba Ghods, Barbara Hersan, Agostino Bruno, Thomas Wright, Nicola Vaia and Ramin Shayan), who concluded with a round table discussion to answer questions and comments from the audience about surgical treatment indications.



In the afternoon, a meeting of patient associations was held, attended by numerous healthcare professionals, who took turns to describe the organisational difficulties faced by the countries they represented. The discussion clearly showed that the disease, only recently recognised as such by the WHO (January 2022), is still not covered (apart from rare exceptions such as Germany) by the public and private healthcare systems of almost all countries. Much remains to be done to build solid and effective care pathways for the many patients affected by this disease. Today, it is estimated that approximately 10% of the female population is affected (in various clinical stages), although there is a lack of reliable global epidemiological data. This favourable circumstance has allowed various patient associations to meet, get to know each other better and share organisational pathways and proposals for the protection of the many patients they represent. National and regional associations continue to spring up spontaneously given the enormous current interest in the disease.



On 6 November, the Congress opened with a report by the author, who presented an overview of the most important issues currently affecting the disease, highlighting the few bright spots in our current knowledge and the many grey areas that require the attention of the international scientific community: in practice, an overview of the topics covered in the scientific sessions, which included lectures, presentations, round tables, workshops and lunch sessions, as well as special and very crowded oral and poster presentation sessions during the three days of the congress.



One of the few certainties that now seems to be shared by the international scientific community is that lipedema is a hereditary disease. In the patient's medical history, it is always necessary to look for other individuals in both families (maternal and paternal, because males act as “healthy carriers”, transmitting the disease but not exhibiting its phenotypic manifestations) who had or have the same phenotype of the disease. All pedigrees, appropriately collected, show a family history spanning several generations.

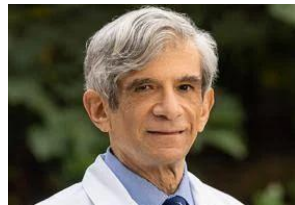
A very rich session (in terms of content and expert speakers) on the basic sciences was then held on the aetiology and pathogenesis of the condition.

Cinti began by highlighting, on the basis of studies conducted on the tissues of affected patients (the result of a study conducted with the author and with plastic surgery), the relationship between endothelial cells and their development into pre-adipocytes and adipocytes, These cells appear to have an increased volume compared to normal adipocytes and have characteristics observed under electron microscopy that distinguish them from normal fat cells and those of obese patients. In fact, lipedema is not a form of localised obesity, as some people still insist on considering it today. Bertelli then gave an overview of current genetic knowledge (the first gene responsible for the disease when mutated, AKR1C1, was discovered by our Italian TEAM). Unlike lymphedema, there are still few studies are underway, both germline (on biological fluids) and somatic (on affected tissues), to identify others that will prove to be responsible for the syndromic forms that are beginning to emerge (similar to what happened with lymphedema) with different overall clinical pictures.



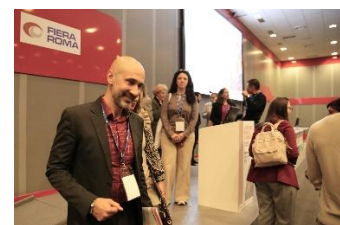
Herbst then presented her studies on the role of activated mast cells in the development of the disease, and Schultz demonstrated the alteration of certain functions of the adipocytes that make up lipedema tissue. Biochemist Cione then recalled how a further study by our Italian TEAM had highlighted a micro-RNA extracted from the diseased tissue, which is particularly active from a

functional point of view, which is being compared with healthy tissue and obese tissue, as well as research into its serum in the three types of subjects described. This substance could represent the first biological marker for the recognition of the disease, which, to date, is only diagnosed clinically. Morawitz, Karnezis and Strauss, from German schools, have therefore indicated some relationships (including multi-omic studies) between epigenetic factors and the development of pathological tissue. Nano Nonkam, Steiner, Rockson and Peault have therefore presented further possible pathogenetic hypotheses.



Then it was Simarro's turn, who attributed hypothalamic inflammation in the satiety centre as a possible cause of eating disorders in lipedema: international literature is also beginning to collect interesting experiences on this topic.

The next session focused mainly on aspects of epidemiology and clinical and instrumental diagnosis. In particular, Szolnoki highlighted some aspects related to microcirculatory alterations present in lipedema and demonstrated with laser Doppler detection; Cannataro and Andrade confirmed, based on their experience, the importance of the information provided by bioimpedance analysis in individual clinical cases; Marina Cestari showed remarkable three-dimensional ultrasound images of lipedema, confirming that a fluid tissue component is always present in lipedema, justifying the term used to identify the disease. Boccardo then highlighted how, in the morphofunctional study of the lymphatic system in lipedema, lymphoscintigraphy and lymphatic MRI are absolutely complementary and useful for a comprehensive examination of individual cases.



Belgrade then explained how lymphofluoroscopic examination with indocyanine green demonstrates different characteristics of fluid progression in subjects with lipedema compared to healthy controls. The session was closed by Shayan, who, with a genetic study, functional analysis and surgical findings, demonstrated a possible role of the lymphatic system in lipedema (statements that sparked a heated discussion in the following session, dedicated to indications for surgical treatment).



The afternoon session on the first day of the Congress saw Ghods illustrate the Potsdam School's surgical approach to the disease. Especially in the more advanced stages of the disease and when

pain is severe and persistent throughout the day, personalised surgical treatment is currently the most effective long-term therapy. The choice of techniques to be used is dictated by a series of objective factors (condition of the tissues, extent of the anatomical areas affected, total volume to be removed) that guide the choice of the most appropriate option.



Ghods' presentation was followed by a session on surgical options and when, how and why to choose them, with the participation of surgeons and non-surgeons. Paula Frederichi opened the session by explaining that, once the characteristics of the disease have been described and the treatment options presented, a conservative choice should always be explored and verified with the patient; depending on how the case evolves, the doctor in charge can always guide the patient towards the most radical choice, if agreed upon. Burgos then emphasised that therapeutic success with the surgical option is achieved by using the most suitable type of liposuction (in his case, water-assisted liposuction), but above all by experienced operators with a good knowledge of the condition. Bruno then described specific techniques, bearing in mind that the concept of localisation sites may need to be reconsidered, as they may not exclude the abdomen itself.



Hersant described her results, both functional and aesthetic, obtained using the Vaser technique. Amron strongly emphasised the importance of a careful and comprehensive assessment of each clinical case in the pre-operative phase. Smith, from the Potsdam School, then highlighted how a large number of cases showed a lack of clinical results on lipedema tissue determined by various bariatric surgery techniques. Low-calorie diets, exercise and bariatric surgery, in fact, have no tangible effect on reducing the areas of the body affected by the condition.



Corrado Cesare Campisi then gave a lecture on the indications and role of minimally invasive surgery in lipo-lymphoedema. At the end of the session, a lively discussion highlighted several aspects. One, perhaps the most important, is that it is not advisable to perform lymphatic diversion or reconstructive surgery in lipoedema, as is still practised in some cases on the theoretical assumption that the lymphatic system plays an important role in the genesis of lipoedema, at the risk of developing secondary iatrogenic lymphoedema, as observed by some of those present in the room.

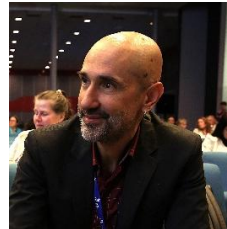


After a break, Cornely presented a video showcasing his thirty years of surgical experience with lipedema patients. He also noted with satisfaction that lipedema surgery has been recognised by the German National Health System since July 2025.

The first day of the conference ended with the final session dedicated to comorbidities. Celletti presented cases of joint hypermobility, which are frequently observed in patients with lipedema, including hypermobile Ehlers-Danlos syndrome. Juliano then pointed out that alterations in thyroid function, often caused by autoimmune thyroiditis (Hashimoto's disease), are not uncommon in patients with lipedema. Another aspect often related to the disease is the alteration of the barrier function of the enterocyte (intestinal dysbiosis), well described by Sciuscio, which, with its clinical manifestations, can lead to the so-called "Leaky Gut Syndrome". Fiengo also confirmed the frequent association of joint hypermobility with lipedema, noting that the deep fascia, as an anatomical structure, is often altered in its macrostructure, suggesting that a common hypothesis of factors linked to a more complex connective tissue pathology may be considered. Cifarelli spoke about altered metabolic aspects, influenced by epigenetics, as co-factors in the genesis of lipedema, presenting a study carried out with other American colleagues, including Thomas Wright. The set of comorbidities described was also observed by Vaquero Romiro, who distinguished their presence in patients with lipedema (more incidents) compared to the healthy control population of a large Spanish sample. The first day of the Congress ended with a series of reflections on the significant amount of information that had been presented during the day. The first day of the conference ended with a series of reflections on the significant amount of information that had been presented during the day.

The second day of the conference was characterised by important and topical issues currently under discussion, first and foremost the possible use of GLP1 (Glucagon Like Peptide 1) agonist drugs. Pennings opened the proceedings with a lecture on the pros and cons of administering these substances. Given that these molecules have been formulated to regulate blood sugar levels and reduce body weight (the ideal patient is an obese diabetic), they are analogous to the substance produced by the body that has the effect of increasing pancreatic insulin production and reducing glucagon production, thereby stabilising blood sugar levels. The natural substance has a short duration of action as it is broken down by an enzyme called DPP-4, which limits its effect. GLP-1 agonists, on the other hand, are modified in such a way as to resist this type of degradation over time, prolonging their effect. These substances have pros and cons. Among the pros, it is certainly worth highlighting the increase in glucose-dependent insulin secretion, reduction of glycosylated haemoglobin in patients with type 2 diabetes, lower risk of hypoglycaemia compared to common oral antidiabetic drugs, reduced appetite and slowed gastric emptying, which can lead to considerable weight loss. For some of these molecules, a reduction in cardiovascular events in at-risk individuals,

a slowing of diabetic nephropathy, and better control of blood pressure, lipid levels and systemic inflammation (also important for patients with lipoedema) have also been reported. Among the disadvantages, it is important to highlight the possibility of nausea, vomiting, diarrhoea and/or constipation and a feeling of early fullness. They also have a high cost, which is borne by patients if used for weight loss and who are not diabetic. In rare cases, pancreatitis (probable cause but still to be proven) and gallstones (especially if weight loss occurs very rapidly) have been reported. They are not recommended for patients with a family history of medullary thyroid carcinoma or multiple endocrine neoplasia (rapid disease progression observed in animals). Finally, parenteral administration rather than oral administration is not appreciated by some patients. This was followed by a round table discussion, with a brief introductory report by Thomas Wright, which was conducted with great participation from all those present in the room, including some patients. The other experts on the panel were Faerber, Cannataro, Simarro, Cobos Salinas, Ziulu, Frederichi and Cochrane, in addition to myself, Pennings and Wright, who moderated. At the end of an intense discussion, with contributions from many participants in the room, the writer summarised by stating that GLP1 agonists can be used in patients with lipedema, but the following aspects still need to be better defined: individual dosage of the single molecules and its dynamic changes over time, duration of treatment, indications in case of side effects, and cost (currently still fully borne by the patient).



This was followed by a presentation by Philipp Kruppa on the creation of the LWA Consensus Document using the Delphi methodology, currently in publication. It constitutes the official position of the LWA Association on all issues related to the disease.

In the subsequent session on guidelines and position papers, Faerber presented the contents of the latest document in the series approved in Germany in 2024, Herbst clarified some points of the US “Standard of Care” published in 2022, Kruppa highlighted some points still under debate among experts, and Forner Cordero compared the various official documents, which fortunately converge on many points. This was followed by a presentation by Herbst on the diagnostic and therapeutic approach in the United States. This was followed by a session on physical treatment for lipedema, during which Sobrinho, Forner Cordero, Frederichi, Mander, Perez, Vaia and Michelini Serena presented their experiences on ozone therapy, elastic compression bandaging, the effects of elastic garments on pain, ultrasound assessment of treatment effects, the effects of combined physical treatment, functional changes in patients before and after surgery, and Tecar therapy, respectively. This was followed by two technical lectures on the importance of controlling the autonomic nervous system in patients with lipedema and one on REAC technology and its effects on modulating the pathophysiology of the condition.

De Jong then gave a lecture on appropriate physical activity for patients with lipedema (medium-low intensity and not high). The session on physical exercise featured various professionals (doctors, physiotherapists and personal trainers) who drew on their experience to highlight certain specific aspects, such as the influence of physical exercise on inflammation (Michelini Serena), the role of necessary personalisation of physical activity protocols (Milano), the importance of educational training by practitioners (Wigg), the role of fascia in improving lymphatic drainage in patients with

lipedema (Scampini), vibration therapy (Monteiro) and possible strategies for harmonising movement in patients with lipedema (Galeno).



The day ended with the first in-person General Assembly of the Lipedema World Alliance, during which, in addition to recalling the fundamental milestones of the association since its inception, the writer, with the continuous dialogue of those present, presented the possible venues and dates for the next biennial LWA Congresses, before moving on to the official appointment of the members of the new Association Board, proposed by the outgoing Board, which had met that same morning.



The third day of the conference opened with Gabriele Faerber's presentation on the nutritional recommendations of the new German guidelines, in which the ketogenic diet plays a role, as recognised by an increasingly solid body of literature on the subject. The next session on nutrition and possible pharmacological approaches featured presentations by Cannataro, Munoz Forner, Lundanes, Jezoriek, Périco Patriani, Forner Cordero, Annunziata and Basciani, who spoke respectively about low-carb diets and nutritional supplements, the effects of anti-inflammatory diets on lipedema, changes in blood sugar and insulin levels in two groups of patients treated with low-carb and low-fat diets, ketogenic diets and their effects on volume and pain, and again on changes in body composition induced by the anti-inflammatory diet, and again on the effects of the anti-inflammatory diet on the volumetric decrease in the areas affected by the disease, the importance of combining diet with appropriate physical exercise, and finally the effect of the ketogenic diet on intestinal dysbiosis and Gut Leake Syndrome.

Three presentations, by Kartt, on behalf of the Lipedema Foundation, on the importance of creating a biobank for the standardisation of data and its use for therapeutic and preventive purposes; by Pouwels on the simultaneous treatment of lipedema and obesity; and by Shmidt on skin remodelling after repeated liposuction procedures, paved the way for the next session: a round table discussion on the therapeutic approach, whether conservative or surgical, attended by Simarro, Herbst, Ghods, Amron, Wright, Shayan, the author, and Faerber. One of the factors in favour of surgical treatment is undoubtedly the pain experienced by the patient. However, another concept, also emphasised by the author, is that once the patient has been clearly explained her condition and the possible forms of therapeutic approach, it is up to the patient herself to choose the option she considers most suitable for her clinical needs.

A subsequent Lecture on an analysis conducted on conservative and surgical treatment, which is also guiding health policy decisions on the disease in Germany, was presented by Mostofizadeh.

Dinnendhal then highlighted the importance (certainly for German schools) of the symptom of pain in the objective diagnosis of the disease. The session on pain characterised the penultimate group of works focused on the symptom of pain. This session featured presentations by Gunduz, Frederichi, Gornati, Pusic, Michellini and a colleague of Borman. They presented a series of statements/questions, starting with the consideration of whether pain in lipedema is neuropathic in nature or not, the effects of resveratrol on pain modulation, the possibility that venous insufficiency, often associated with this disease, also contributes to the perception of pain, the impact of pain on patients in their daily lives, the relationship between pain, body mass index and clinical stage of lipedema (not decisive), the correlation between plasma pregnenolone levels and pain (with a proportionally inverse relationship), and an analysis of the impact of pain itself on quality of life.



The last session was moderated by Kartt, who transformed it (following the example of other round tables already tried in previous sessions) into a panel discussion attended by Kruppa, Crescenzi, Cifarelli, Cochrane and representatives of UK and US patient associations; once again, there was considerable audience participation. In light of the pressing requests from patient associations, an attempt was made to identify possible areas of research and further study of issues relating to the disease. These certainly include genetics, but also clinical trials of possible new drugs and possible conservative therapies and, when indicated, surgical therapies. The involvement of healthcare institutions (both public and private) and pharmaceutical companies themselves is fundamental. They are called upon to play more dynamic but also more flexible roles in improving the quality of life of the many patients (estimated at around 10% of the female population worldwide in various clinical stages!) who follow the developments in clinical and experimental research with apprehension and interest.



Alongside the plenary sessions, there were seven interesting oral presentation sessions, two poster sessions with discussions, four workshops and a lunch session, with a total of over 250 original scientific contributions presented. The abstracts can be consulted on the official websites (Congress, Organising Secretariat and Society).



The Congress closed with the writer's thanks to all participants and in particular to all those who made the event possible: from the organising secretariat, GC Congressi, which had to manage the organisation of the event with over 870 participants from 40 countries, to the technicians present in the various rooms, to the Fiera di Roma, which hosted the initiative, to the companies that were present directly or indirectly, to those who contributed in any way to the promotion of the event. But special thanks go to Mojtaba Ghods, Jonathan Kartt, Philipp Kruppa, Manuela Lorenzo Marquez and Paula Frederichi for the commitment and enthusiasm with which they followed the various organisational stages from a scientific and technical point of view. Finally, I would like to thank my large family, and first and foremost my wife and daughters, who supported me during this long and complex preparatory period.



See you in two years, probably in Virginia (USA), for another exciting event where discussions between experts, researchers, patients and companies in the sector will allow us to share experiences and news that will hopefully be useful for the ever-improving management of the disease.

Sandro Michelini  
Presidente Lipedema World Alliance

Rome 28 November 2025