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NATIONAL LYMPHEDEMA NETWORK, INC.
225 Bush Street, Suite 357
San Francisco, CA 94104
Telephone 415-908-3681
Website www.lymphnet.org
E-mail nlm@lymphnet.org

Mission Statement:

The mission of the National Lymphedema Network is to create awareness of lymphedema through education and to promote and support the availability of quality medical treatment for all individuals at risk for or affected by lymphedema.

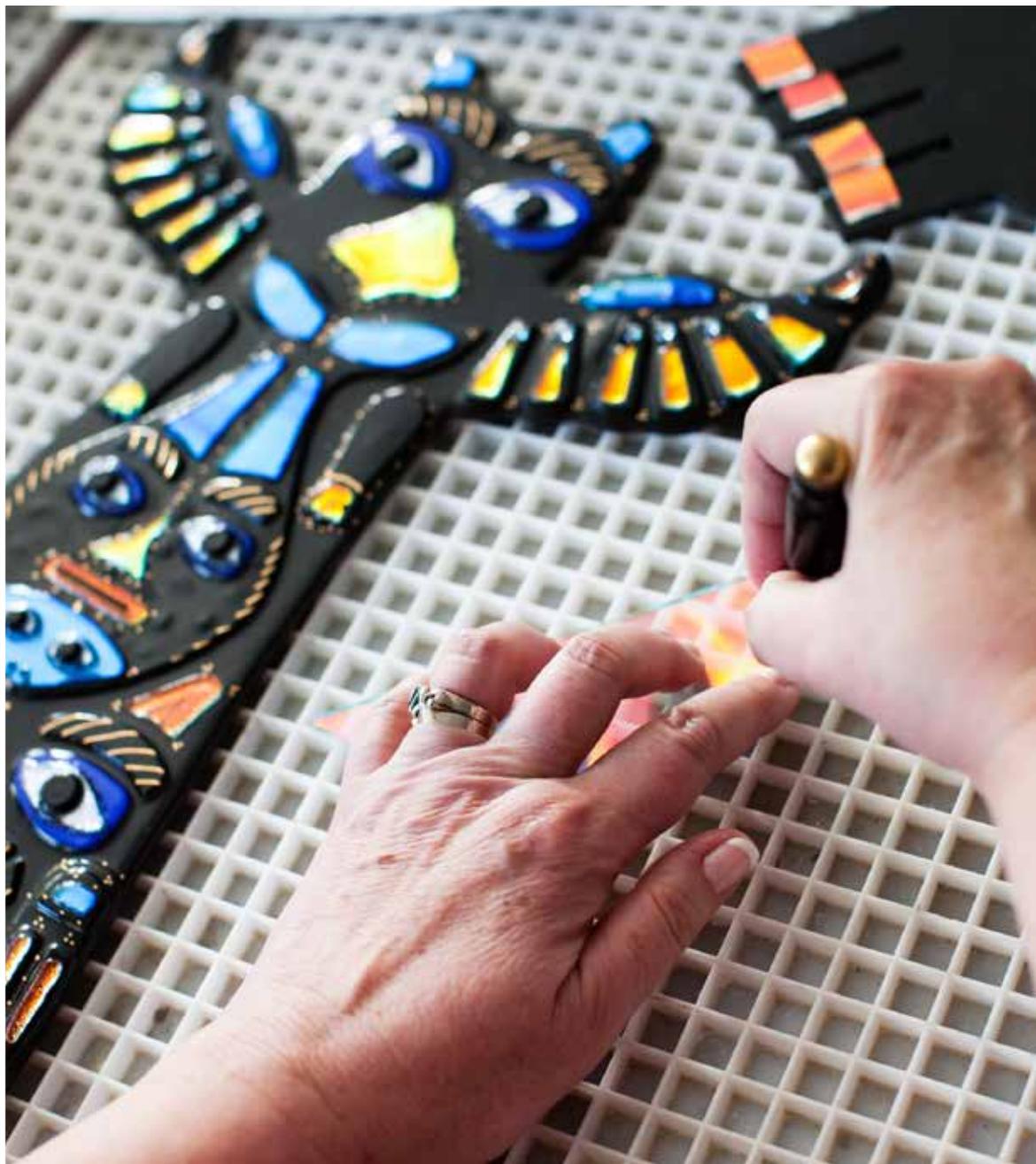
The NLN is dedicated to:

- * promoting research into the causes, prevention, and treatment of lymphedema;
- * securing adequate insurance coverage for medically necessary, safe, and effective treatment;
- * expanding the number and geographical distribution of lymphedema treatment facilities and certified therapists.

To achieve these goals, the NLN disseminates information about lymphedema to healthcare professionals so they can appropriately counsel their patients on its avoidance, and prescribe safe, effective treatment for those affected by this condition. The NLN also provides this information to the general public.



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NATIONAL LYMPHEDEMA NETWORK

225 Bush Street, Suite 357
San Francisco, CA 94104
Telephone 415-908-3681
Fax 415-908-3813
800-541-3259
Website www.lymphnet.org
Email nlm@lymphnet.org

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The goal of this publication is to provide information specific to the needs of lymphedema patients and health care providers.

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**DEADLINE FOR
January/March 2016**

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All copy, renewals, and payments must be received no later than

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While writing my President's message for our 4th quarter of LymphLink, and preparing for the upcoming 25th World Congress of Lymphology in NLN's hometown San Francisco, I vividly remember when I first became aware of the ignorance of swollen extremities. I quickly realized the enormity of the disease and the need for awareness and education in the lymphatic system. I reached out locally, and nationwide to learn more and was shocked that there was not one doctor in the US who could provide any guidance about diagnosis or treatment options. As a nurse I simply could not accept that there was no support and treatment for this patient population! I found out about the 12th International Society of Lymphology Congress in Tokyo and decided to attend the Congress in 1989. At that time only scientists attended the Congress. As a nurse I wondered whether I belonged there and did not feel welcome. Twenty-seven years later, the NLN is proud to join forces with the ISL and Sentinel Lymph node Oncology Foundation in bringing together key researchers, clinicians, therapists, patients, patient advocates and a large delegation of industry partners from 33 countries for this historic congress. If you were not able to attend, we will publish a detailed report on the Congress in the next LymphLink.

This issue of LymphLink covers the "state of surgery for lymphedema". In the last decade there has been a dramatic increase in overall interest among surgeons around the world regarding surgical interventions to manage lymphedema. Patients are hopeful that surgical options might reduce the amount of daily self-care necessary to control their condition. However, we need clinical trials and evidence based research with long term follow-up to know whether surgery can in fact reduce the self-care necessary to control lymphedema. All of this takes time and close follow-up.

We are pleased that Dr. Jay Granzow, a well-respected plastic surgeon in the LE community, is sharing his great interest and expertise in this issue. Dr. Granzow provides a detailed review of the various surgical procedures, and stresses that proper patient selection for surgery as well as coordination with a lymphedema specialist are critical to achieve optimal outcomes.

Dr. Hakan Brorson, also well known in the literature and lymphology world shares his work in Liposuction. Dr. Brorson shocked the LE community in the early 1990's with this invasive procedure. Today many surgeons from around the world are trained by him and see excellent results. The key is wearing a well fitted garment 24/7.

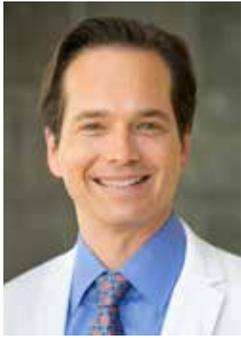
Dr. Granzow also describes two case studies. The first is a young woman with Stage 3 primary unilateral leg LE who did not respond to CDT, and opted to have Suction Assisted Protein Lipectomy (SAPL). The second is a 42-year-old woman with breast cancer-related lymphedema (BCRL), who had Vascularized Lymph Node Transfer (VLNT) and simultaneous DIEP flap breast reconstruction. Both patients had excellent results.

Dr. Robert Klein covers the Q corner and provides us with excellent practical guidelines to prepare for VLNT. Dr. Jaume Masia, a surgeon from Barcelona, shares his interesting research in pre-operative imaging and clinical assessment between 2007 and 2014. Thank you both for sharing your work with our readers.

Julie Soderberg, a LE therapist, talks about her work in surgery and the importance of pre- and post operative care and close follow up with the patients and home therapists. Joanne da Costa, a nurse/patient shares her amazing journey with BCRL and recurrent episodes of infections that caused worsening of her LE and negative impact on her daily activities.

Continues on page 33

Cover Photo: Hands of a patient with right arm lymphedema. The patient is a professional artist specializing in glass sculptures. The lymphedema was not well controlled with a compression garment. In addition, glass shards from her work continually lodged under the garment, causing irritation and infections. Following a successful vascularized lymph node transfer (VLNT), the patient was able to control the lymphedema and work successfully without the use of a compression garment.



The Current State of Surgery for Lymphedema

By: Jay W. Granzow, MD, MPH, FACS

Associate Professor of Surgery, UCLA Division of Plastic Surgery, Manhattan Beach, CA

Our current knowledge of the lymphedema disease process has advanced tremendously in recent years. While non-surgical management remains the first line standard of care, safe surgical alternatives now exist which can provide effective and long-term improvements.

At first, lymphedema swelling is composed mostly of lymphatic fluid. In this early stage, the swelling is more amenable to conservative treatment. Patients have also responded well to lymphedema surgery to reverse or greatly decrease the fluid swelling. Over time, the lymphatic fluid can bring about permanent deposits of solids in the tissues that are more difficult to treat. Lymphedema swelling also greatly increases the risk of dangerous infections, called cellulitis, which can be severe in patients with lymphedema. Arm or leg swelling can often progress to cause functional impairments that interfere with work and activities of daily living.

Effective lymphedema surgeries have existed for many years and continue to be refined and improved. We have found that best results are achieved when surgery is performed as part of a comprehensive treatment system incorporating specialized lymphedema therapy before and after surgery. The success of lymphedema surgeries also highly depends on the training, experience, and relevant expertise of the surgeon and lymphedema therapist.

Modern lymphedema surgeries are much more precise and less invasive than previous radical attempts at a surgical cure. Older procedures, such as the Charles Procedure, involved aggressive removal of the skin and deeper tissues down to the level of the muscle fascia, with skin grafts placed over the raw areas. Fortunately, such invasive procedures are now reserved only for a very small number of extreme cases involving thickened, pendulous, and inflamed skin and tissues.

Lymphedema surgeries have been shown to produce significant and lasting reductions both in the size of the affected arm or leg and also the amount of therapy and compression garment use required for treatment. No single technique is optimal for all presentations. Rather, careful patient selection after a complete course of conservative lymphedema therapy has been completed is critical. Individualized lymphedema therapy integrated into the treatment plan before and after surgery also is

essential in achieving excellent results. [1-3]

The fluid predominant portion of lymphedema may be treated effectively with surgeries that involve transplantation of lymphatic tissue, called vascularized lymph node transfer (VLNT), or involve direct connections from the lymphatic system to the veins, called lymphaticovenous anastomoses (LVA). VLNT and LVA are microsurgical surgeries that can improve the patient's own physiologic drainage of the lymphatic fluid, and we have seen the complete elimination for the need of compression garments in some of our patients. These procedures tend to have better results when performed when a patient's lymphatic system has less damage. Therefore, patients with early stage lymphedema tend to have more impressive results with these procedures.

Some studies have shown variable results when VLNT or LVA are used to reduce volume. [4-6] We find better results using conservative therapy and compression first to reduce the excess fluid volume, and then using VLNT or LVA to reduce the amount of compression and therapy needed to maintain the volume reduction.

Vascularized Lymph Node Transfer (VLNT)

VLNT surgery involves the microsurgical transfer of a small number of lymph nodes and surrounding tissue from another part of the body, called a donor site, to the area affected by lymphedema. Multiple donor sites have been reported and include the groin, torso, supraclavicular area (near the neck above the collar bone), and submental areas (underneath the chin). [5,7,8]



Figure 1: Patient with right arm lymphedema following treatment for breast cancer with bilateral mastectomy, right lymph node dissection, and radiation therapy. A) Arms prior to surgery; B) 4½ -year stable result following VLNT performed together with a DIEP flap for breast reconstruction. She requires no daily garment or therapy.

Surgery using VLNT is thought to improve lymphedema through multiple mechanisms. Surgical scar release and interposition of healthy tissue to prevent reaccumulation of scar tissue are performed as part of the surgery if scar tissue is accessible, such as in the axilla. Regrowth of remaining lymphatics into the transplanted lymphatic tissue and an additional direct pumping mechanism also have been described. [9-12] Anti-inflammatory effects of lymph node transfer flaps also contribute, including decreased tissue fibrosis and increased expression of growth factors such as VEGF-C. [13]

This surgery has been shown in well-established medical literature for the last 15 years to be effective in reducing the swelling, symptoms, and associated problems with lymphedema. The need for ongoing lymphedema therapy and compression garment use can be decreased significantly. The incidence of cellulitis and infection in the affected extremity has also been shown to decrease. [1,14]

Safety and surgical expertise are critical to minimize the rare risk of lymphedema occurring at the donor site. [15-18] The use of reverse lymphatic mapping also can minimize this risk by mapping the lymph nodes draining the arm or leg closest to the lymph node flap donor site, using

a radioactive tracer similar to that used in lymphoscintigraphy, or using specialized blue dye taken up by the peripheral lymphatics. [1,3,19] During the dissection of the lymph node-containing flap, the lymph nodes draining the arm or leg are thus identified and preserved and only a small number of peripheral lymph nodes are harvested.

Lymphaticovenous Anastomosis (LVA)

LVA surgery is the direct connection of lymphatic vessels to nearby veins. These connections as very small, usually much less than 1mm in diameter, and require supermicrosurgical expertise. The procedure was first described in 1969 by Yamada and subsequently by O'Brien in the 1970s. [20-21] Significant advances in supermicrosurgical technique for LVA were further described by Koshima. [22] Connections usually are made into veins with competent valves to allow the one-way movement of excess lymph back into the venous system. In the peripheral parts of the arm or leg, closer to the hands or feet, single or multiple superficial lymphatics are connected to veins. In the proximal areas, closer to the armpit or groin, the lymphatics are larger and fewer, and larger connections typically are performed. The location and types of connections can vary considerably

from patient to patient and are dependent on the patient anatomy, surgeon experience, and the progression of the lymphedema disease itself. Since no donor site is required and only a fraction of the lymphatic vessels in the affected arm or leg are connected, LVAs tend to be the least invasive and have the lowest overall surgical risk and recovery among any of the lymphedema surgeries. [23-26] This also makes LVA idea for use in prevention of future lymphedema. [27]

Lymphaticolymphatic Bypass (LB)

First described in 1986 by Baumeister et al,

LB involves connection of lymphatics in the affected arm or leg directly to healthy, functioning lymphatic vessels in a donor area. The donor lymphatic vessels are mobilized for long distances from the surrounding tissues, the distal (far) ends divided and the entire length of vessel tunneled past the area of lymphatic blockage. The authors reported improvements in both limb volumes and the lymphatic transport index, and volume reductions were easier to achieve in arms than legs. This type of procedure presents the theoretical risk of new lymphedema at the donor harvest site. [28-29]

Suction Assisted Protein Lipectomy (SAPL)

The solid-predominant swelling often found in later stages of lymphedema can be treated effectively with a surgery called suction-assisted protein lipectomy (SAPL). SAPL surgeries allow removal of lymphatic solids and fatty deposits that are otherwise poorly treated by conservative lymphedema therapy, VLNT, or LVA surgeries.

SAPL has been proven to be an effective and long-term solution for lymphedema in many patients. The procedure is different from standard cosmetic liposuction, which is not suitable to treat lymphedema. SAPL has been described using various names including circumferential suction assisted lipectomy (CSAL), liposuction in lymphedema, and limpho-liposuction. [3,30] First introduced in 1987, SAPL techniques have been refined over the years and have produced significant objective benefit in clinical trials with long-term follow-up. This surgery greatly decreases the incidence of severe extremity cellulitis and hospitalizations requiring intravenous antibiotics to treat such infections. Medical literature overwhelmingly supports the safety and efficacy of this surgical treatment. We know of no studies or reports which have shown the procedure to be ineffective or harmful to patients, if performed properly by an experienced surgeon with close coordination and post surgical treatment by a lymphedema therapist with SAPL experience. [31-34]

Published studies document a 75% reduction in the incidence of



Figure 3: Patient with 20-year history of congenital chronic, solid-predominant lymphedema of the left leg. A) Legs prior to surgery; B) Postoperative result. The patient has a stable reduction of approximately 108% (treated leg slightly smaller than unaffected leg) 2 years after SAPL surgery.

infections and an average 90 to 110% reduction in excess volume. These include a 17-year, prospective study of 120 patients with arms treated with SAPL, and an 8-year, prospective study of 41 patients with legs treated with SAPL. In our own published series, we have reported average infection reductions of about 80% and excess volume reductions of 111% in arms and 86% in legs. Statistically significant reductions in lymphedema impact on daily activities, ability to work, improved limb function, reduced lymphedema-specific emotional distress, and a clear improvement in patient quality of life have also been shown. [1,35-37]

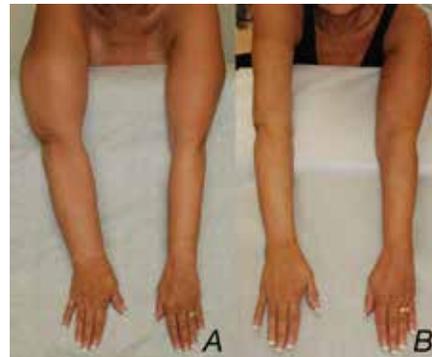
The safety of SAPL surgery has been studied in medical literature, which found the function of the lymphatics to be unaffected by the surgery. [38] In our experience, surgery appears also to improve the lymphatic drainage in the arm or leg after healing has occurred, and we have had no cases in which the patient's lymphedema has worsened from the procedure. Continuous compression garment use under the care of a trained lymphedema therapist following the surgery is essential to prevent the reaccumulation of the pathologic lymphedema solids and fat. Again it must be emphasized that SAPL is very different from cosmetic liposuction in many ways, including the type and amount of lymphedema therapy required, the way the procedure is performed,

the length of the surgery and solid materials removed, and need for progressively smaller, specialized, custom-fitting garments after surgery. Lymphedema therapy performed by a specialized lymphedema therapist with specific experience with the SAPL is also essential to proper outcome following the procedure and cannot be substituted with a simple set of postoperative written instructions to the patient or therapist.

Patient Selection

Because the different lymphedema surgeries address different aspects of lymphedema swelling, proper patient selection is vital to the success of any surgery for lymphedema. LVA and VLNT best address the fluid portion of lymphedema swelling which typically is more prevalent during the early stages of the disease process. SAPL best removes the solid component of the swelling, usually found in later, chronic cases. For example, an arm or leg affected by late-stage, chronic lymphedema which never reduces in size to even close to that of the opposite, unaffected side even on a patient's best day with maximum lymphedema therapy is very likely to be characterized by solid, rather than fluid swelling. In such a case, significant volume reduction is much less likely with LVA or VLNT, and much more likely with SAPL. For example, in a study by Damstra, LVAs performed for patients with solid predominant lymphedema found little additional improvement in reduction of excess volume. [39] However, LVA and/or VLNT intended to decrease the amount of compression garment use and therapy required (rather than to decrease excess volume) could be performed after SAPL removes the stagnant lymphedema solids first. [40]

Figure 4: Patient with a 19-year history of chronic lymphedema following history of right breast cancer treated with lumpectomy, lymph node dissection and radiation therapy. Patient required daily prophylactic antibiotic due to large number of recurrent arm cellulitis infections. A) Prior to surgery; B) 25 months following combination of SAPL followed later by left VLNT. She achieved a stable reduction in volume of approximately 103% (treated arm slightly smaller than unaffected arm), patient is out of compression garment 8-12 hours every day, had no further cellulitis with no prophylactic antibiotics needed.



The best candidates for lymphedema surgery are patients who have tried and failed a properly planned and administered lymphedema therapy regimen that usually includes of manual lymphatic drainage (MLD), fitted compression garment use, and bandaging. One or more courses of complete decongestive therapy (CDT) usually have been performed. Good candidates are willing to continue with lymphedema therapy before and after any surgical procedure, although it is often possible to reduce the therapy and compression garment requirements after a successful surgery. Poor candidates for lymphedema surgery are patients that have not or are unwilling to have lymphedema therapy, who are looking for a "quick fix" type of procedure, or who are greatly overweight. Obesity and morbid obesity usually produce poor surgical outcomes not only with lymphedema surgeries but also with surgeries in general. Meaningful weight loss through a coordinated program, which could include appropriate weight-loss surgery, should be concluded prior to consideration for a lymphedema surgical procedure.

Importance of Integrated Lymphedema Therapy

Lymphedema therapy that is carefully integrated into any surgical treatment plan is of paramount importance. A lymphedema

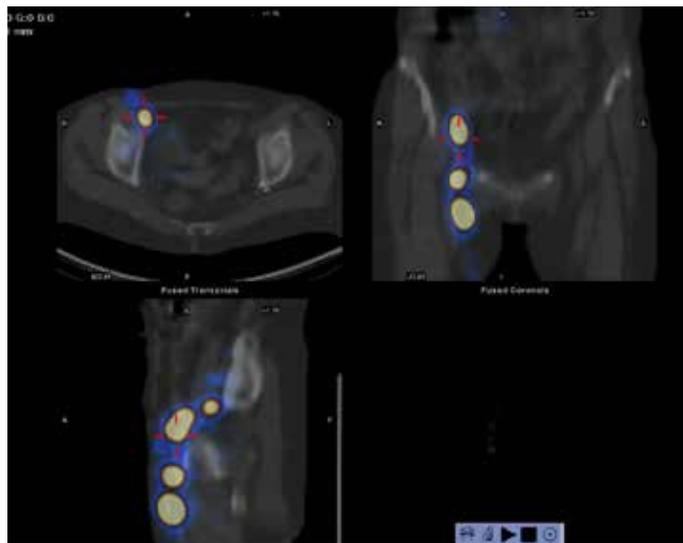


Figure 2: Imaging of donor site lymph nodes obtained as part of reverse lymphatic mapping to minimize risk of lymphedema at a surgical lymph node donor site. Lymph nodes containing tracer as seen in these images are left intact and not taken during the VLNT procedure.

surgeon must work closely with a lymphedema therapist to insure the best lymphedema therapy course is given both before and after any surgical procedure. This is especially true for the SAPL procedure, where pre- and postoperative planning, measurements, and lymphedema therapy are vital to the success of the surgery. Ideally, long-term lymphedema therapy is administered by the patient's local lymphedema therapist under the direction of the lymphedema surgeon or surgical lymphedema therapist.

Combined and Staged Lymphedema Surgeries

Effectively treating lymphedema surgically now includes using multiple surgeries with proper therapy. Physiologic procedures such as VLNT and LVA can be combined during the same operation or in sequential operations for increased effectiveness. [3,41]

Staged procedures can also

be used to treat both solid and then fluid components of lymphedema separately. For instance, VLNT/LVA can be performed once healing after the SAPL surgery is complete to help address the persistent accumulation of lymphatic fluid. We have documented significant reductions both in excess limb volume and also in the requirement for postoperative garment use in medical literature with the staged SAPL and VLNT combination of procedures. [40]

On the Horizon

Research efforts include implantation of nanofibers across scarred areas of lymphatic obstruction tested in an animal model. [42] Possible advantages of such an approach would be lack of a donor site and possibly shorter surgery times. Limitations include lack of long-term results and lack of healthy patient tissue transfer to decrease the chance for new scar formation. Also, the need for defined scar site to be bypassed, such as the case in lymphedema after

gynecological malignancies, would limit application.

Growth factors, such as VEGF-C, have been shown to be related to lymph vessel growth and increased lymph transport parameters such as capillary filtration capacity. [43] The use of growth factors to stimulate growth of lymphatic vessels in an affected area has been studied in animals for many years. However, long term use and safety in humans has not been established. [44-47]

Overall, multiple effective surgical options for lymphedema exist. Surgical treatments are not a "magic bullet", and should be pursued in the context of continuing lymphedema therapy and treatment to optimize each patient's outcome. When performed by an experienced lymphedema surgeon as part of an integrated system with expert lymphedema therapy, safe, consistent, and long-term improvements can be achieved.

DrJay@LymphedemaSurgeon.com
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Circumferential Suction-Assisted Lipectomy is the Only Surgical Procedure that Can Normalize a Large Chronic Non-Pitting Lymphedema

By: Håkan Brorson, MD, PhD

Department of Clinical Sciences, Lund University, Plastic and Reconstructive Surgery, Skåne University Hospital, Lund University, Malmö, Sweden.

Introduction

Circumferential suction-assisted lipectomy (CSAL) techniques have proved to be a valuable tool in various aspects of reconstructive surgery. While it is clear that conservative therapies such as complex decongestive therapy (CDT) and controlled compression therapy (CCT) should be tried in the first instance, options for the treatment of late-stage lymphedema that is not responding to this treatment is not so clear. Surgical procedures have been developed and described to address various clinical aspects of the pathophysiology of lymphedema. Microsurgical techniques are promoted to provide physiologic drainage of excessive lymphatic fluid. In many late-stage cases though, adipose tissue deposition and fibrosis are the predominant manifestations of the disease process. Surgical therapies aimed at adipose tissue removal can provide significant symptom relief for affected patients. CSAL enables complete removal of the deposited adipose tissue leading to complete volume reduction both in early and in late stage lymphedema.

Is there any evidence for adipose tissue in lymphedema?

Clinicians often believe that the swelling of a lymphedematous extremity is purely due to the accumulation of lymph fluid, which can be removed by the use of noninvasive conservative regimens, such as CDT and CCT. These therapies work well when the excess swelling consists of accumulated lymph, but do not work when the excess volume is dominated by adipose tissue as can be seen in a chronic lymphedema (Figure 1).¹ Computer tomography and dual-energy X-ray absorptiometry has shown a high content of adipose tissue

in patients with arm lymphedema following breast cancer treatment.^{2,3} Recent research shows that chronic inflammation leads to deposition of excess adipose tissue.^{4,5} Microsurgical procedures using lymphovenous shunts, lymph vessel transplantation, and vascularized lymph node transfer,⁶⁻¹⁰ do not remove adipose tissue; thus complete reduction cannot be achieved with these procedures.

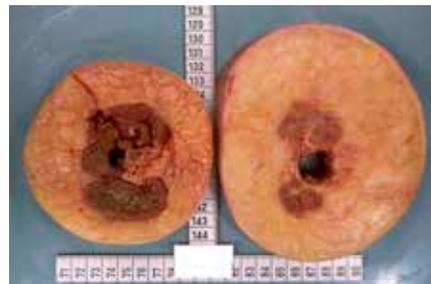


Figure 1. Transection of a normal (left) and a lymphedematous arm (right) showing the abundance of adipose tissue. (Courtesy: Dr C-H Håkansson, Department of Oncology, Lund University Hospital)

When can CSAL be performed?

Candidates for this procedure are patients who have been optimally treated with conservative therapy and show no or minimal pitting (1–2 mm) (Figure 2). Some patients, due to ineffective conservative treatment, can show more pitting. As such, some patients selected for CSAL techniques may have some edema present, and in some cases around 4–5 mm of pitting in an arm lymphedema and 6–8 mm in a leg lymphedema can be accepted if the therapist cannot reduce it further. If the presence of edema fluid is the major disease manifestation, the lymphedema must be treated conservatively to transfer it into a non-pitting state, where the excess volume consists of adipose tissue.

Extremity volumes are measured and if the excess volume is still troublesome, CSAL is carried out. CSAL should be used as a method to remove fat, not fluid, even if theoretically it could remove the accumulated fluid in a pitting lymphedema without excess adipose tissue formation.

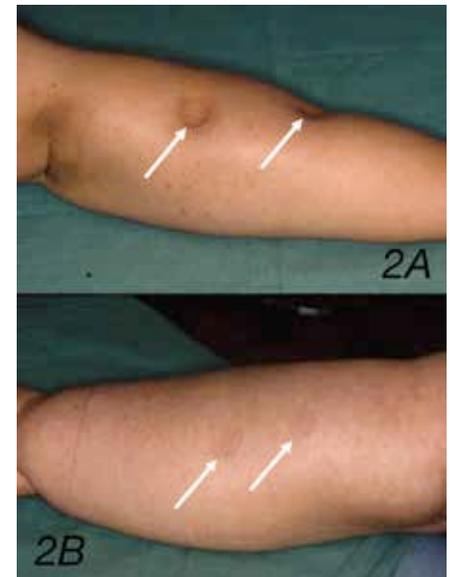


Figure 2a. Marked lymphedema of the arm after breast cancer treatment, showing pitting several centimeters in depth (stage I edema). The arm swelling is dominated by the presence of fluid, i.e. the accumulation of lymph.

Figure 2b. Pronounced arm lymphedema after breast cancer treatment (stage II-III edema). There is no pitting in spite of hard pressure by the thumb for one minute. A slight reddening is seen at the two spots where pressure has been exerted. The 'edema' is completely dominated by adipose tissue. The term 'edema' is improper at this stage since the swelling is dominated by hypertrophied adipose tissue and not by lymph. At this stage, the aspirate contains either no, or a minimal amount of lymph.

Compression garments

Early and continuous compression therapy is imperative to the success of the CSAL protocol. Two custom-made compression garments are measured

preoperatively using the healthy arm or leg as a template and one set is put on during surgery.

Preoperative investigations

Limb volume measurements are a mainstay evaluation tool in the treatment protocol of lymphedema. Volumes of both extremities are always measured at each visit using water plethysmography, and the difference in volume is designated as the excess volume.^{1,11} Particular to the lower extremity, venous color Doppler examination is used to rule out any venous insufficiency, which can influence leg swelling. In addition, the combined occurrence of venous and lymphatic insufficiency is a known entity affecting some patients. Lymphoscintigraphy provides useful information on not only the anatomy, but also on the lymph transport. We use it mostly in patients with primary lymphedema and in patients with unknown leg swelling, for example, when lipedema is suspected.

Surgical technique

The use of power-assisted CSAL facilitates the removal of adipose tissue and reduces surgeon-fatigue, particularly in the lower extremity, which can be more demanding to treat. To minimize blood loss, a tourniquet is utilized in combination with tumescence, which involves infiltration of 1–2 L of saline containing low-dose adrenaline and lidocaine.^{12,13} Through approximately 15–20 3–4 mm-long incisions, CSAL is performed using 15- and 25-cm-long cannulas with diameters of 3 and 4 mm. When the arm or leg distal to the tourniquet

has been treated, a sterilized custom-made compression sleeve and glove is applied to stem bleeding and reduce postoperative edema. The tourniquet is removed and the most proximal part of the upper arm or leg is treated using the tumescent technique.¹³ and then the compression sleeve is pulled up to compress the proximal part of the upper arm. The incisions are left open to drain through the sleeve. The aspirate contains 95% fat in mean (Figure 3). Operating time is approximately two hours for arms and 3 hours for legs (Figure 4).

Long term outcome

The techniques to achieve the most desirable results have changed with increasing experience. Today, chronic non-pitting lymphedema of up to 4.5 L in arms and more than 8 Lin legs in excess volume can be effectively removed by use of CSAL (Figure 5).¹⁴ Maximal reduction is usually achieved between three and six months. Long-term results have not shown any recurrence of the arm swelling with the permanent use of compression garments (Figure 6).^{1,11,14,15-18} In addition, promising results can also be achieved for leg lymphedema (Figure 7), with maximum reduction usually occurring at around twelve months (Figure 8).^{19,20}

Postoperative regimen: Controlled Compression Therapy

Garments are removed two days postoperatively so that the patient can take a shower. Then, the other set of garments is put on and the used set is washed and dried. The patient repeats this after another two days before discharge. The patient alternates between the two sets of garments, changing them daily so that a clean set is always put on after showering and lubricating the arm. Washing ‘activates’ the garments by increasing the compression due to shrinkage. The patient is seen after one month when arm volumes are measured.

At the three-month visit, the arm is measured for new custom-made garments. This procedure is repeated at six, nine, and 12 months. When complete reduction is achieved, sleeves without straps are ordered. If complete reduction has been achieved at six months, the nine-month control may be omitted. If this is the case, a quantity sufficient for six months of garments are prescribed, which normally means double the amount that would be needed for three months. When the excess volume has decreased as much as possible—usually the treated arm becomes somewhat smaller than the normal arm—and a steady state is achieved, then new garments can be prescribed using the latest measurements. In this way, the garments are renewed three or four times during the first year. Two sets of sleeve and glove garments are always at the patient’s disposal; one is worn while the other is washed. Thus, a garment is worn permanently, and



Figure 3. The aspirate contains 90–100% adipose tissue in general. This picture shows the aspirate collected from the lymphedematous arm of the patient shown in Figures 4, 5, and 7 before removal of the tourniquet. The aspirate sediments into an upper adipose fraction (90%) and a lower fluid (lymph) fraction (10%).



Figure 4. Liposuction of arm lymphedema. The procedure takes about two hours. From preoperative to postoperative state (left to right). Note the tourniquet, which has been removed at the right, and the concomitant reactive hyperemia.



Figure 5a. A 67-year-old woman with a non-pitting arm lymphedema for 5 years. Preoperative excess volume 3580ml. Figure 5b. Postoperative result.



Figure 7. Primary lymphedema: Preoperative excess volume 6630ml (left). Postoperative result after two years (right).

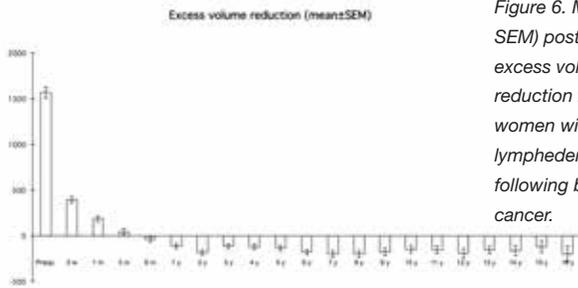


Figure 6. Mean (\pm SEM) postoperative excess volume reduction in 124 women with arm lymphedema following breast cancer.

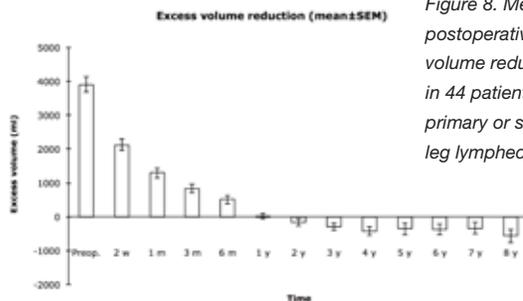


Figure 8. Mean postoperative excess volume reduction in 44 patients with primary or secondary leg lymphedema.

treatment is interrupted only briefly when showering and, possibly, for formal social occasions. The life span of two garments worn alternately is usually 4–6 months. For arms, complete reduction is usually achieved after 3–6 months, often earlier. After the first year, the patient is seen again after six months (1.5 years after surgery) and then at two years after surgery. Then the patient is seen once a year only, when new garments are prescribed for the coming year, which is usually four garments and four gloves (or four gauntlets). For active patients, 6–8 garments and the same amount of gauntlets/gloves a year are needed. Patients without preoperative swelling of the hand can usually stop using the glove/gauntlet after 6–12 months postoperatively.

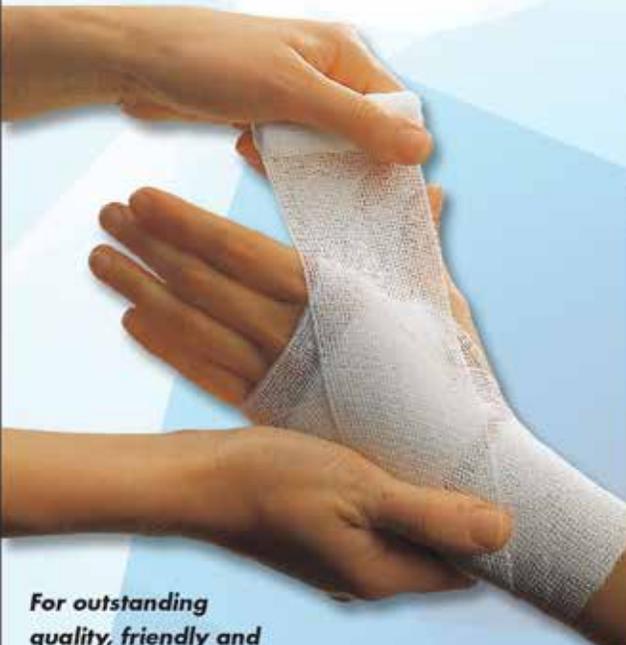
For legs we use up to two or three compression garments on top of each other, depending on what is needed to prevent pitting. A typical example is compression class 3 with a panty, on top of this, a leg long garment, compression class 2, and a below-the-knee garment, compression class 2. Thus, such a patient needs two sets of 2–3 garments. Depending on the age and activity of the patient, two such sets can last for 2–4 months. That means that they must be prescribed 3–6 times during the first year. After complete reduction has been achieved, no panty is needed and stay-up garments are ordered, and the patient is seen once a year when all new garments are prescribed for the coming year.

Summary

- Excess volume without pitting means that adipose tissue is responsible for the swelling.
- As in conservative treatment, the lifelong use (24 h a day) of compression garments is mandatory for maintaining the effect of treatment. Since all patients comply with this before surgery nothing new is added.
- Adipose tissue can be removed with CSAL. Conservative treatment and microsurgical reconstructions cannot do this, thus CSAL is the only surgical method to achieve complete reduction of the excess volume of the lymphedematous limb.

hakan.brorson@med.lu.se
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CASE STUDY 1

Use of Suction Assisted Protein Lipectomy (SAPL) for Treatment of Chronic, Non-Compressible Lymphedema of the Leg

By: Jay W. Granzow, MD, MPH, FACS

Associate Professor of Surgery, UCLA Division of Plastic Surgery, Manhattan Beach, CA

The patient is a 34-year-old woman with a history of congenital lymphedema of the left leg for 17 years. She previously had complete decongestive therapy (CDT). However, her response to lymphedema therapy was poor and she stopped going to therapy. She wore a class 2 over-the-counter compression garment during the day and a Reid Sleeve at night. She did not perform compression bandaging.

Her left leg was massively larger than her right leg and made fitting normal clothes or shoes impossible. The patient had constant leg discomfort and it became worse with standing, exercise, or performing even simple activities of daily living. She was limited in the number of hours that she could work and found it increasingly difficult to participate in family activities with her two young children. The volume of her leg continued to increase slowly over time. Otherwise, the patient reported no other relevant past medical history.

On initial presentation, her lymphedema was characterized by predominantly solid volume excess. Her left leg had a volume excess of 5079 cc compared to the unaffected right leg and pitting was minimal. The patient's knee range of motion was limited to 90 degrees of flexion. She was given the Lymphedema Life Impact Scale (LLIS) questionnaire (reference) and she scored a 58 on a scale of 18 to 90, which calculated to 56% functional, physical and psychosocial impairments.

Preoperative goals included reduction of excess volume, reduction of discomfort, increase in range of motion, and increase in ability to work and exercise normally.

In preparation for surgery, the patient was diligent with bandaging every day and lost approximately 10 pounds by increasing her cardio and weight training regimen. This regimen reduced the volume excess from 5079 cc to 2976 cc, a volume reduction of 41%. Afterwards, suction assisted protein lipectomy (SAPL) surgery was performed, with approximately 3500 cc of aspirate removed. Short stretch compression bandaging was placed in the operating room at the end of the procedure by a surgical lymphedema therapist. Following surgery, the patient remained hospitalized for two nights pursuant to the SAPL surgery protocol. Before the patient was discharged from the hospital, the surgical lymphedema therapist replaced the short stretch compression bandaging with custom-fit, flat knit, compression garments ordered prior to surgery. Before discharge, the patient demonstrated that she was able to care for her leg and able to remove and replace her compression garment.

After one week, the patient returned to her home lymphedema therapist for further lymphedema therapy. As the postoperative swelling reduced, the compression garments were also remade to accommodate the smaller leg circumferences.

At five weeks after surgery, the volume excess in the patient's leg had reduced to 433 cc, and further reduced

to a negative 436 cc by 10 weeks after surgery (a 109% decrease in excess volume from her initial presentation). The volume of her leg has remained stable since that time. The patient's ability to work and exercise has normalized and discomfort has been eliminated. She has been able to fit normal clothes, including jeans and boots, for the first time since she was a teenager. She continues to wear a class 3 thigh high (first layer) and a class 2 thigh high (second layer) custom-fit, flat knit compression garments 23 hours per day. Her knee flexion range of motion is now within normal limits and her LLIS score is now 21 or 4%.

Discussion

Patients, such as the one presented here, who have suffered from lymphedema for a long period of time usually present with a volume excess that is solid predominant with some fluid component. Therefore, treatment focused first on lymphedema therapy to treat and remove the excess fluid component. Weight reduction also likely reduced the solid component. In this case, reduction of



Figure 2 Sample of lymphedema aspirate removed from left leg during SAPL procedure

the fluid component plus initial weight loss reduced approximately 41% of the initial volume excess. Additional reductions in volume excess would have been limited without the surgical removal of the excess solids with the SAPL procedure.

Overall, the patient's goals and expectations have been met or exceeded. Her excess volume reduction is 109% and her function and her psychosocial well-being have improved. Close integration of appropriately aggressive lymphedema therapy, bandaging, and custom-fit compression garment use by a trained lymphedema therapist together with continued downsizing of the custom-fit garments were essential to achieving the patient's excellent outcome. The requirement for continued compression following surgery - first to remove the postoperative edema and then to prevent lymph fluid accumulation - is standard for the SAPL surgery. She will be a candidate for a second stage physiologic procedure, such as a vascularized lymph node transfer (VLNT) or lymphaticovenous anastomosis (LVA) surgery in the future to decrease the future need for compression use.

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Figure 1 Both legs prior to surgery



Figure 3 Both legs 4 months following SAPL procedure for left leg

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CASE STUDY 2

Vascularized Lymph Node Transfer (VLNT) with Deep Inferior Epigastric Perforator (DIEP) Flap Breast Reconstruction for Treatment of Right Arm Lymphedema

By: Jay W. Granzow, MD, MPH, FACS

Associate Professor of Surgery, UCLA Division of Plastic Surgery, Manhattan Beach, CA

The patient is a 45-year-old woman with a history of right arm lymphedema following treatment for breast cancer. Treatment included six cycles of chemotherapy, followed by bilateral skin-sparing mastectomy with right axillary lymph node dissection. Immediate breast reconstruction with bilateral tissue expander placement was performed at the time of the mastectomies. She was then treated with radiation therapy to the right chest wall and axilla that was completed approximately three months after the initial surgery.

After the initial healing was complete, the patient developed a cellulitis infection in the right breast requiring eventual removal of the right tissue expander. The left tissue expander was left in place. Eventually, she also had cellulitis on the left side but this was treated with antibiotics and the tissue expander was saved.

Approximately three months after completion of the radiation therapy, the patient began to notice swelling in her right arm. Fortunately, the patient's primary care physician had ordered a right arm compression garment as a precaution. She was diagnosed with lymphedema and referred to a certified lymphedema therapist.

Lymphedema treatment included a complete course of CDT including bandaging, MLD, and compression garment placement. Initially, the lymphedema responded well but the patient needed to wear a circular knit, 30 to 40 mm compression garment every day to keep the symptoms from returning. She wore no garment at night and performed bandaging only when flying. She did develop a stiff cord in

her forearm that extended from the forearm to axilla. She had no history of cellulitis and required lymphedema therapy at least two times per month for one hour each session.

Other past medical history included hypothyroidism and thalassemia trait. She had no bleeding issues related to her previous procedures. Past surgical history included uterine myomectomy per low transverse incision, laparoscopic appendectomy and hysterectomy/removal of tubes and ovaries. Medications included daily Aromasin and baby aspirin, which were stopped before surgical treatment.

On initial presentation, her radiated right chest wall skin was discolored, irregular in contour and closely adherent to the chest wall. The left breast skin was soft with the initially placed tissue expander in good position. A well-healed, low transverse abdominal incision was present from the previous abdominal procedures along with multiple small scars from the laparoscopic access points.

The right arm was only minimally larger than the unaffected left arm. A firm cord of soft tissue was clearly palpable under the skin extending from the forearm to the axilla and she had discomfort with shoulder movement with shoulder flexion and abduction decreased from 180 to 140 degrees. No significant pitting was present.

Preoperative goals included reconstruction of bilateral breasts, reduction of the need for compression garment use and lymphedema therapy, improvement of shoulder motion and release of the subcutaneous cord.

Surgical treatment consisted of debridement and release of the scar and soft tissue cord in the right axilla, removal of the adherent inferior chest wall skin, and removal of the left tissue expander. Left breast reconstruction was performed with a left abdominal deep inferior epigastric perforator (DIEP) flap. Right breast reconstruction and right axillary lymph node reconstruction were performed with a right combined DIEP/VLNT flap. Five months after the initial surgery, a planned, second stage breast reconstruction procedure for revision of the abdominal donor site and breast reconstruction flaps with left nipple reconstruction was performed. Since the right breast reconstruction result was smaller than the left due to the need for right chest wall skin removal, additional volume was added with fat grafting from the hips and flanks as part of the right breast revision for



Figure 1 Preoperative views of arms and chest wall. The right arm has only mild swelling. The right chest has significant deformity due to loss of previous tissue expander from infection and radiation therapy.



Figure 2 Postoperative views 20 months after left DIEP flap and right DIEP/VLNT and planned second stage revision of breast reconstructions and abdomen.

symmetry. Right nipple reconstruction is planned in the future.

Both breast reconstructions have excellent shape and symmetry, and the abdomen has significantly improved shape and contour. Following the initial procedure, the patient progressively decreased the use of the compression garment. By six weeks, she was no longer using the garment daily and reserved its use only for more strenuous activities such as cooking for long periods of time. The fibrous subcutaneous band released during surgery did not return. Her shoulder and elbow range of motion returned to normal at approximately 8 weeks after surgery. The patient did feel intermittent soft tissue fullness at the right elbow that spontaneously resolved without further treatment. At this time, she manages her lymphedema by performing self-MLD daily and wearing her garment when she exercises or travels. She has not required therapy from a CLT in a year. Just recently, she returned to check in with her lymphedema therapist to have a full MLD session after returning from a trip from the east coast.

Discussion

This case presents surgical treatment for both breast reconstruction and also lymphedema. The combined bilateral DIEP flap with right VLNT allowed simultaneous treatment of both issues with the same series of procedures.

The state of the patient's chest wall skin and the history of radiation therapy required that any further breast reconstruction be performed using the patient's own tissue rather than a tissue expander and/or implant. The abdomen is a preferred site for such tissue, and the patient's excess abdominal skin and fat provided an excellent donor site. The right nipple reconstruction was delayed to allow both revised breast reconstructions to settle to their final position to allow proper placement of the nipple position.

As in this case, a history of prior abdominal surgery does not necessarily preclude breast reconstruction with an abdominal soft tissue flap such as a DIEP flap. Fortunately, most of the patient's previous abdominal

procedures were performed with less invasive approaches. A standard appendectomy approach may have precluded a combined DIEP/VLNT flap. In those situations, a two-step procedure may be considered, with a VLNT performed first and a bilateral DIEP performed two or more months thereafter.

Prompt diagnosis and treatment of the patient's arm lymphedema by a certified lymphedema therapist (CLT) controlled the patient's initial swelling and prevented the accumulation of excess lymphatic fluid and solid material. Prompt referral for VLNT

surgery allowed for placement of the transferred lymph nodes prior to atrophy and sclerosis of the affected arm's remaining lymph channels and further progression of the lymphedema disease process. The transferred lymph nodes continue to be effective in clearance of lymph fluid. This greatly decreased the need for continuing lymphedema therapy and eliminated the need for continuous daily compression garment use. She is still advised to continue compression garment use during at-risk activities such as flying or gardening.

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Barcelona Lymphedema Algorithm for Surgical Treatment (BLAST)

By: Jaume Masia, MD, PhD, María Miranda, MD, Gemma Pons, MD

Department of Plastic Surgery, Hospital de la Santa Creu i Sant Pau (Universitat Autònoma de Barcelona), Barcelona, Spain.

Breast cancer related lymphedema (BCRL) is a chronic condition that affects quality of life, a prevalence of 21% has been reported to occur on breast cancer patients^[1]. Currently, there are several conservative and surgical options of treatment for lymphedema, the latter include reconstructive and palliative (liposuction) procedures. The indications for each procedure are the cornerstone to achieve positive outcomes. We will review in this paper the indications included in the Barcelona Lymphedema Algorithm for Surgical Treatment (BLAST) that we have established for liposuction and for the reconstructive procedures (vascularized lymph node transfers (VLNT)^[2] and lymphatico-venular anastomosis (LVA)^[3] that we perform in our center.

A detailed medical history and clinical examination are essential to determine the lymphedema stage according to the International Society of Lymphedema (ISL) which is an indicator of the severity of the disease^[4]. Following an accurate clinical evaluation, the main information required to individualize the surgical treatment is to evaluate the remaining functionality and the morphology of the lymphatic system of each patient. For that purpose we perform a preoperative assessment using imaging techniques.

Indocyanine green (ICG) fluorescence lymphography is of paramount importance since it allows us to evaluate the function of the lymphatic system^[5]. Immediately after injection of the ICG dye we can observe the contrast ascending towards the axilla that is an indicator of a preserved contractility, and few minutes later we can determine the presence of dermal back flow. This information is of crucial importance

during the preoperative assessment because only a patient with functioning lymphatic channels can be considered a potential candidate for reconstructive lymphedema surgery. ICG lymphography is also used to evaluate the anatomical distribution of the lymph channels and the existence of superficial collateral pathways, that information is highly variable between patients and the presence of collateral lymphatic circulation would be a protective factor against lymphedema^[6]. ICG lymphography is performed in the outpatient clinic during the first consultation and depending on the results lymphoscintigraphy (LS), magnetic resonance lymphography (MRL) and computed tomography (CT) angiography might be required.

ICG lymphography permits a maximum depth of study of 1 cm from the surface and for that reason in advanced cases with important fat hypertrophy, diffuse dermal backflow or in obese patients in which we need to study the deeper tissues, MRL complements the information provided by ICG lymphography. MRL is performed using a gadolinium-based contrast. At predetermined points along a reference line marked from the acromion to the nail of the thumb, passing through the central point of the cubital fossa, hyperintense markers are placed on the skin surface to map the lymphatic channels. Mapping is facilitated by 3D MRL. The combination of ICG lymphography and MRL provide information to identify the lymphatic channels with adequate anatomical and functional characteristics for successful LVA. MRL also allows imaging of the deep lymphatic system.^[7]

Lymphoscintigraphy is used to support the indication of VLNT to the axilla when absence of axillary tracer

uptake is found. When remaining lymph node functionality is found in the axilla the cubital fossa or the wrist can be used as receptor areas for VLNT. CT scan is obtained when a VLNT is indicated and it is used to evaluate the lymph nodes at inguinal donor area. We select the most cranial and lateral inguinal nodes to diminish the risk of secondary donor site morbidity and because this area has rich vascularization from the superficial epigastric system or the superficial circumflex iliac system.

When the lymphatic channels are still functioning, we perform the Combined Surgical Treatment (CST), which includes LVA and VLNT or LVA only. When the patient requires breast reconstruction and a reconstructive surgical treatment for lymphedema we use a combined DIEP/SIEA flap with groin VLNT with double vascularization. We anastomose the inferior epigastric vessels to the internal mammary vessels according to our standard breast reconstruction protocol. To provide an adequate vascularization for the transferred lymph nodes in all the patients receiving a VLNT, we anastomose the superficial epigastric system or the superficial circumflex iliac system from the groin VLNT to axillary vessels other than the thoracodorsal vessels.

We have found that patients with medial predominant drainage without collateral dorsal vessels or with less than 6 lymphatic channels after mastectomy and axillary dissection are more likely to develop lymphedema. In these patients we propose the concept of Total Breast Anatomy Restoration (TBAR) as a preventive procedure. For TBAR, we perform immediate breast reconstruction accompanied by lymph-lymphatic anastomosis between the stumps of the upper limb lymphatic vessels

remaining after lymph node dissection and the afferent vessels from transplanted lymph nodes.

In later stages of lymphedema, when no remaining lymph channel function is observed, we opt for lympho-liposuction to reduce hypertrophic adipose and fibrous tissue using a technique similar to that previously described by Brorson.^[8]

Reverse lymphatic mapping

In order to reduce the risk of causing a lower limb lymphedema at the donor site, ICG-lymphography is used for the reverse mapping of the lymph node drainage of the donor lower limb when performing groin lymph node transfers isolated or in combination with breast reconstruction with an abdominal flap. It helps us to differentiate intraoperatively the lymph nodes that drain the donor lower limb from the superficial lymph nodes that we can harvest. Also, before raising the vascularized lymph node flap, before incising the skin, we inject patent blue V dye intradermally above and below the inguinal fold in the potential drainage area to visualize better the superficial lymphatic vessels during dissection.

Our Results

The management of lymphedema in our department can be divided in two periods of time depending on the indications for reconstructive lymphedema surgery we used. The outcomes clearly improved in the

second period of time as described below.

From June 2007 to December 2011, the indication for lymphedema surgery was clinical and all the 106 patients with stage I and II BCRL according to the ISL criteria that we treated in our department received a reconstructive surgical treatment. Fifty nine patients were treated with LVA, 7 patients with VLNT, and 40 patients with both. Preoperative versus postoperative excess circumference was reduced between 12% and 86.7% (average 39.72%) while the arm circumference decreased between 0.9 and 6.1 cm (average 2.75 cm). Ninety-eight patients had a perceived improvement, while 8 patients did not report any significant changes^[9]. If we assess these results carefully looking for an objective improvement, we realize that an excess circumference reduction of less than 20% or the perceived improvement that the patients report of their quality of life (less heaviness, pain relief) are not always a consequence of the surgery. It could be due to an increased awareness of the patients of the disease and the general care that postoperative period under the control of the surgeon requires, because similar outcomes have been reported when only conservative treatments are provided. From our first group, in only 46 patients we could find a perimeter reduction over 20%, which might be attributed to the surgery.

From June 2012 until June 2014, we started to use reconstructive

surgical procedures only in patients who had a remaining functionality of the lymphatic system determined by ICG lymphography. From the 94 patients who received a surgical treatment for lymphedema in that period of time only 44.7 % of the patients received reconstructive techniques, 22 patients underwent LVA, 16 patients TBAR and 4 patients a CST. Finally 52 patients underwent lymph-liposuction. The rate of preoperative versus postoperative excess circumference decreased between 42 and 89.6% (average 64.2%), while the circumference of the arm diminished from 2.9 – 6.1 cm (average 3.85 cm). All patients reported a perceived objective improvement.

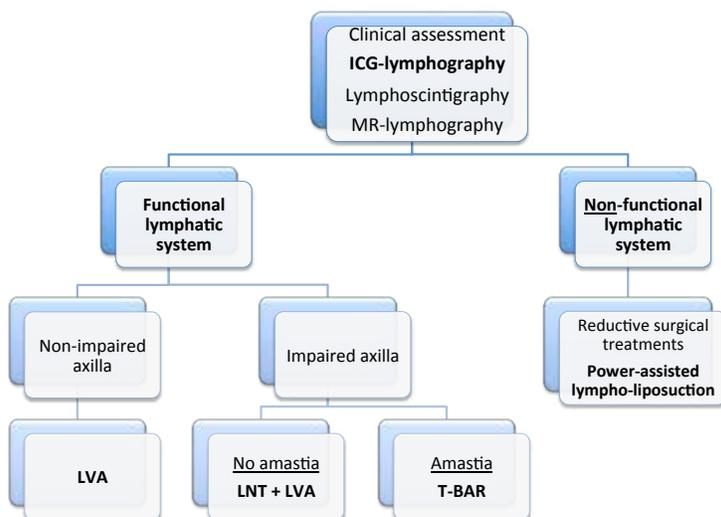
Summary

The BLAST has been proposed based on the results we have obtained after years of experience treating patients with lymphedema and its main purpose is to individualize the treatment of the patients with lymphedema. Detailed clinical and imaging preoperative assessment should be performed to determine the most suitable surgery depending on the functionality of the lymphatic system. Only the patients with a residual lymphatic functionality would benefit from reconstructive options while for patients with advanced lymphedema and failure of the lymphatic system a reductive technique is more appropriate.

jmasia@santpau.es

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BCN Lymphedema Algorithm for Surgical Treatment - BLAST





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LISTING GUIDELINES: *In 2001, the Lymphology Association of North America (LANA) was founded to establish minimum competency standards for lymphedema therapists and provide a national standardized certification examination (CLT-LANA). This examination is available twice annually. Preliminary minimum standards have been set by LANA, and the NLN has adopted them for qualification of training programs, treatment centers and therapists in the United States. As of November 1, 2002, the NLN requires lymphedema training programs to offer a minimum of 135 hours of intensive training (1/3 theoretical, 2/3 practical) in order to qualify for a listing in the NLN Resource Guide (referred to as Sponsorship). Lymphedema therapists (independents) must have completed a recognized 135-hour training program, and treatment centers must have on staff at least one lymphedema therapist who has completed such a program.*

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Director: Bonnie B. Lasinski, PT, MA, CI, CLT-LANA

Medical Director: Marvin Boris, MD
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Website: www.vodderschool.com
Director: Robert Harris, HND, RMT, CLT-LANA

Medical Director: Christine Heim, MD
Course Length: 160 hours, 20 days
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Director: Guenter Klose, CI,CLT-LANA
Medical Director: Kathleen Francis, MD
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Medical Director: Harry McCoy, MD
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Classes Held: Across the U.S.

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Fax: 732-290-2278
Email: info@nortonschool.com
Website: www.nortonschool.com
Director: Steve Norton, CLT-LANA

Medical Director: Andrea Cheville, MD
Course Length: 135 hours, 9 days
Classes Held: Across the U.S.

Student Codes: MD,RN,PT,PTA,OT, OTA,MT,S

Program Codes: C,P,A

Resource Guide Legend

The following codes appear in the Treatment Center and Manual Lymphatic Drainage Therapist listings. Codes indicate the school attended by each on-staff therapist. If school attended by a therapist is not an NLN-Sponsoring Training Course, only an asterisk (*) will appear in the listing, indicating that no information has been provided. See the Training Course column for program descriptions.

- A = Academy Of Lymphatic Studies**
- B = Boris-Lasinski School, Casley-Smith U.S. Affiliate**
- G = Klose Training & Consulting**
- M = Monarch Continuing Education (formerly Lymphedema Care Specialists, LLC)**
- N = The Norton School of Lymphatic Therapy**
- S = Complex Lymphatic Therapy Courses, Casley-Smith US Affiliate**
- V = Dr. Vodder School-North America**
- W = International Lymphedema & Wound Care Training Institute**
- ◆ = CLT/LANA Certified**
- SPECIAL NOTE:**
Training Programs no longer in existence:
- C = Casley-Smith School**
- I = Lymph Drainage Therapy ~ Upledger Institute**
- K = Kessler Lerner LE Academy**
- LL= Lerner LE Services Academy**
- T = The Lymphedema Consultants**

TRAINING PROGRAM LEGEND

Program Codes

- (indicate what is covered in the program)*
- C = Complete Program (Manual Lymph Drainage, bandaging, garment review, exercise, diet/nutrition, self care, skin care)**
- P = Use of pumps reviewed**
- A = Additional types of compression garments/devices reviewed**

Student Codes

- (indicate who is eligible to attend the course)*
- MD = Doctor**
- RN = Nurse**
- NP = Nurse Practitioner**
- PT = Physical Therapists**
- PTA = Physical Therapist Assistant**
- PA = Physician Assistant**
- OT = Occupational Therapists**
- OTA = Occupational Therapist Assistant**
- MT = Massage Therapists**
- ATC = Athletic Trainers Certified**

(Note: Massage therapists should contact the school for minimum practical hours and experience required to attend this course.)

Diagnostic Centers

University of Arizona Medical Ctr with Healthsouth Rehabilitation Institute of Tucson Tucson, AZ
 Marlys H. Witte, MD
 Michael J. Bernas, MS 520-626-6118

Treatment/Diagnostic Centers

Lymphedema Ctr [1*] Santa Monica, CA
 Emily Iker, MD 310-829-7472

NorthShore University Health System Evanston, IL
 [5A,5G,1LL,4N,2*,10◆]
 Joseph Feldman, MD, CLT-LANA 847-570-2066

Spectrum Health Lymphedema Program [3A] Grand Rapids, MI
 Richard Hodgson, MD
 Sally Klenk, PT 616-468-6800

Physicians

Jay W. Granzow, MD, MPH, FACS Plastic & Reconstructive Surgery
 Manhattan Beach, CA 310-882-6261

Nancy A. Hutchison, MD,CLT-LANA [G/◆] Physical Medicine and Rehabilitation
 Minneapolis, MN 612-863-2123 or 612-863-8947

Treatment Centers

ALABAMA

HealthSouth Lakeshore Rehabilitation Hosp [1A,5*,5◆] Birmingham
 Cheryl Pierce, OT, CLT-LANA
 Nancy McCracken, PT,CLT-LANA 205-868-2290

ARIZONA

CORAL (Center for Oncological Rehabilitation and Lymphedema) Phoenix
 [3G,1◆]
 Natalie Fogelson, PT, MSPT, CLT-LANA 623-580-9323

Yavapai Regional Medical Center Prescott
 [1C,1*,1◆]
 Donna Hannah, OTR/L,CLT-LANA 928-771-5131

HealthSouth Scottsdale Rehabilitation Hospital Lymphedema Treatment Program [1S,1G,LANA] Scottsdale
 Andrea Brennan, OTR/L,CLT-LANA,DAPWCA
 Emma Casey PT, CLT 480-551-5454 or 480-551-5436

Lymphedema Treatment Center at Honor Health Scottsdale
 [1A,1N,2◆]
 Christy Kim, PT,CLT-LANA 480-323-1100

ARKANSAS

Arkansas Lymphedema and Therapy Providers [1G,1A,2◆] North Little Rock
 Troy Alberson, MSPT,CLT-LANA 501-772-3224

CALIFORNIA

City of Hope National Medical Ctr Duarte
 [2G,3*,3◆]
 Jennifer Hayter, MA,OTR/L,CLT-LANA 626-256-4673 x 62412

TAG Physical Therapy El Segundo
 [1N,1V]
 Cathy Tarte, PT,OCS
 Richelle Drake, CLT 310-426-9570

Saint Agnes Cancer Center Lymphedema Program Fresno
 [1A,1◆]
 Denise L. Ketcham, PT,CLT-LANA 559-450-5500

National Lymphedema Center Manhattan Beach
 [1G,2N,1◆]
 Julie M. Soderberg,MPT,ATC,CSCS,CLT-LANA
 Shayla Storz 310-882-6261

Providence Holy Cross Medical Ctr Mission Hills
 [1N,1*,1A,1◆]
 JoAnne Shahrazi, OTR/CLT-LANA 818-898-4529
 Kathy Caplan, RPT/CLT 661-288-5925

Hoag Memorial Hospital Presbyterian Newport Beach
 [1A,3N,1◆]
 Leslie Craner, PT, CLT
 Anita Swigart, PT 949-764-5676

St. Joseph Hospital, Lymphedema Center [1A,1C,1LL,2N] Orange
 Jeanne Fehring, PT, CLT 714-734-6288

Casa Colina Centers for Rehabilitation [5N,1◆] Pomona
 Kathy San Martino, PT,CLT-LANA
 Debbie Huskey, PT,CLT 909-596-7733 x3660

Motion Recovery Physical Therapy, Inc. [3A,1G,1◆] Sacramento
 Amy Flinn, PT, CLT-LANA
 Angela Blaikie, PT, CLT 916-649-0700

Sharp Rehabilitation Center San Diego
 [2V]
 Carol Long OTR/L, CLT
 Samantha Collieran OTR/L,CLT 858-939-3938

St. Mary's Medical Center Outpatient Therapies [2A,1G] San Francisco
 Fiona McCusker, PT 415-750-5900

Eden Medical Center for Outpatient Rehab Services San Leandro
 [1A,1V,1◆]
 Marina Aquino Villarey, OTR/L,CLT 510-727-3178

Central Coast Lymphedema Therapy [1A,1G,2◆] San Luis Obispo
 Leslyn Keith, MS,OTR/L,CLT-LANA 805-782-9300

San Ramon Regional Medical Center San Ramon
 [1V]
 Lisa Berman, MS, PT
 Nicole Midtlyng, PT 925-275-8442

Dominican Lymphedema Management Program [2A,2G,3N,1S,1♦] Santa Cruz
Karen Ashforth, MS,OT,CLT-LANA 831-457-7082

Central Physical Therapy
[1A, 1 LANA] Stockton
Frederick "Chip" Hanker, PT, MPT 209-473-2383
Virtu Arora 805-788-0805

Conejo Valley Physical Therapy and Lymphedema Center
[2A] Thousand Oaks
Jennifer Vonarb, MPT, CLT
Tessa Waggoner, MS, PT, CLT 805-497-9300

Torrance Memorial Medical Center
[1N,1V,2♦] Torrance
Sheryl Au, PT 310-517-4665

Coastal Community CA Center Lymphedema Program
[2G,1♦] Ventura
Claudia Steele-Major, PT, CLT 805-652-5612
Dawn Meiklejohn, OTR/L,CLT 805-658-5459

COLORADO

Memorial Hospital, University of CO
[1G,1N,1*,2♦] Colorado Springs
Brad Chewakin
Kim Duncan 719-365-5642

Health Ctr of Integrated Therapies & Physical Med Department
[2G,2V,2♦] Longmont
Karen Martin, RMT, CLT-LANA 303-651-5188
Jodi Winicour, PT, CLT-LANA 303-485-4163

CONNECTICUT

Rehabilitation Associates, Inc.
[2A,1V,2♦] Fairfield
Jan Hollerbach, MA,OTR/L,CLT 203-384-8681
Tricia Warner OT,CLT-LANA 203-922-1773

Greenwich Hospital
[2A,1N] Greenwich
Janet Freedman, MD 203-863-4290
Heather Leigh Studwell, MS,OTR/L
203-863-3291

Middlesex Hospital - Physical Rehabilitation Center
[4N,1*] Middletown & Essex
Michelle Aafedt, MS, OTR/L 860-358-2700
860-358-3970

Norwalk Hospital Rehabilitation Services [2G] Norwalk
Diana Rich, PT 203-852-3400

The Stamford Hosp Outpatient Rehab at Tully Health Ctr
[1K,2N,1S] Stamford
Jennifer Rokicki, OT
Gina Aiello, PT 203-276-2660

FLORIDA

Aventura Hospital and Medical Center [1A] Aventura
Trudy Ferguson-Pitters, RPT,CLT,MHSA
305-937-5802

Northwest Medical Outpatient Rehab
[1A,1V,1♦] Margate
Cathy Kleinman-Barnett, MOTR/L,CLT-LANA,
954-978-4180

Wuesthoff Rehab Services
[7A,1N,2♦] Melbourne/Rockledge
Adam F. Rhoads, PT 321-752-1500
or 321-433-0288

Therapy For You Lymphedema Clinic
[1A,2N] Ocala/Lady Lake
Meenu Jethwani, OTR/L, CLT 352-237-0073
352-391-9500

St. Lucie Medical Ctr Lymphedema Clinic [3A, 1N, 3♦] Port St. Lucie
Pamela Bayliss, CLT-LANA 772-398-1928
Tiffany Heisler PT, CLT-LANA 772-398-1999

Healing The Generations, Inc.
[2A] St. Petersburg, Clearwater & Tampa
Nadine Verdebout, PT
Wouter Vanderhorst, PT 727-535-6746

Space Coast Lymphedema Clinic
[2A,1♦] Viera
Rosanne Bessenaire PT,CLT-LANA
Marcia Jeddrie OTR/L, CLT 321-241-6543

Florida Hospital Zephyrhills
[2A,1N] Zephyrhills
Evelyn Lopez, OTR
Nasly Benavides, PT 813-783-6154

GEORGIA

Northside Hospital (Atlanta, Forsyth, Cherokee, Alpharetta)
[3A, 1N, 1S] Atlanta
Andrew Wasely, PT, 404-236-8030
Gillian Wolfson, PT 770-844-3650

Bradley Whiteside Rehabilitation
[1A,1♦] Dalton
Margaret Seacrest, PT,CLT-LANA 706-272-6199

St. Joseph - Candler Hospital
[1A,1♦] Savannah
Mary Couquet Felchlin, CLT-LANA,COTA/L,BA
912-819-8822

The Rehabilitation Institute at Memorial Health [2A,2♦] Savannah & Pooler
Corie Michelle Turley, PT,CLT-LANA
Cheryl Lynn Armstrong, OTR/L,CLT-LANA
912-350-7128

HAWAII

Kapi'olani Women's Center
[1N, 1♦] Honolulu
Nicole Tramontano, DPT,CLT-LANA 808-527-2588

ILLINOIS

NovaCare Rehabilitation
[4N] Chicago, Mt. Prospect, Oak Park
Karyn Holtz, PT 312-640-2473
Thomas Rosinski, PT 847-398-1775

Elmhurst Memorial Healthcare
[2A,2G,2♦] Elmhurst
Janet Benedict PT,CLT-LANA
Deanna David PT,CLT-LANA 331-221-6044

Northshore University HealthSystem
[5A,5G,1LL,4N,2*, 10♦] Evanston
Joseph Feldman, MD,CLT-LANA 847-570-2066

Northwestern Medicine-Delnor
[3G,1V,2♦] Geneva
Christine Wietrzykowski, MHS,PT,CLT-LANA
630-208-4592

Ingalls Hospital [3G,1N,1*,1♦] Harvey
Sandy Collins, PT,CLT-LANA 708-915-8465

Loyola Center for Rehabilitation
[4A,1*,2♦] Maywood & Oakbrook
Julie K. Nelson, PT,DPT,CLT
Elizabeth Russell PT 708-216-5300 x2

Palos Community Hospital
[4G, 1N, 1♦] Palos Heights
Caroline Leflar, PT,CLT
Alicia Ferguson, PT,CLT-LANA 708-923-5050

Swedish American Health System, Outpatient Therapy Services
[2A, 1G, 1N, 3♦] Rockford
Janet Davis, PT,CLT-LANA
Jennifer L. Wuori, PT,CLT-LANA 815-489-4590

Midwest Rehabilitation Services, Ltd. [2V,2♦] Woodridge
Surekha Bhangare, PT, CLT 630-910-8480

INDIANA

Franciscan Alliance: St. Elizabeth Central [2A, 1G, 1N, 2 LANA] Lafayette
Regina R. Pilotte, OT 765-423-6885

Saint Joseph Regional Medical Center Outpatient Therapy
[2G,1N, 1♦] Mishawaka/Plymouth
Joanne M. Hartman, PT,CLT 574-335-6212

IOWA

Methodist Jennie Edmundson Lymphedema Center [1S,1♦] Council Bluffs
Mary-Ellen Bartels, PT,CLT-LANA 712-396-6025

Genesis Cancer Center - Oncology Rehab and Lymphedema
[3*] Davenport
Christine H. Beuthin, PT, DPT, GCS
Sarah Mullins, PTA, CLT 563-421-1470

Lymphedema Clinic, Iowa Methodist Medical Center
[2A,1G,1N,3♦] Des Moines
Nancy Fellows, PT, CLT-LANA
Kari Seivert, OTR/L, CLT-LANA 515-241-6839

4 ~ Resource Guide

KENTUCKY

St. Elizabeth Medical Ctr
[1A,1G,1*,3♦] Edgewood
Lynne A. Daley, PT, CLT-LANA
Teresa Ann Westendorf, PTA,CLT-LANA
859-301-2168

Baptist Health Louisville Lymphedema Clinic [1A,1G,2I,2N,1♦] Louisville
Renee Elieff, OTR/L
Kathy Doelling, PT 502-897-8137

Norton Cancer Institute Lymphedema Program [4A] Louisville
Jenni Haynes, PT, CLT 502-394-6455
Gwen Danhauer, OTR/L, CLT 502-629-4062

LOUISIANA

Baton Rouge General Medical Ctr [1A] Baton Rouge
Chris Perkins, LOTR 225-763-4050

MAINE

Mid Coast Hospital [2A] Brunswick
Lisa Clark, MS, OTR/L 207-373-6175

MARYLAND

Chesapeake Lymphedema Center [2A] Bel Air
Raymond Cooper, OT
Anthony Malek, PT 410-838-5964

Adventist Healthcare Physical Health and Rehabilitation
[1A, 9G, 2N] Rockville
Jennifer Nulton, OT,CHT,CLT
Shiona Thompson, MOT,OTR/L,CLT
240-826-2160

MASSACHUSETTS

Baystate Lymphedema Program
[1N] East Longmeadow
Barry Rodstein, MD,MPH,CLT
Michelle Procencher, OTR/L,CLT 413-794-1150

Reliant Medical Group Lymphedema Treatment Ctr [1G,3M] Worcester
Michelle Wellen, PT,DPT,CLT
Joanna Donato, DPT,CLT 508-856-9510

MICHIGAN

University of Michigan Lymphedema Treatment Program
[1A,3G,3N] Ann Arbor
Katherine Konosky, OT,CLT-LANA
734-936-7070

Mary Free Bed Rehabilitation Hospital [3G] Grand Rapids
Jennifer McWain, PT
Betty Houtman 616-456-4842

Spectrum Health Lymphedema Program [3A] Grand Rapids
Richard Hodgson, MD
Sally Klenk, PT 616-468-6800

Lakeland Health Care – Lymphedema Services [1A,1G,4N,3♦] St. Joseph
Leann Jewwel, MS,PT,CLT-LANA
269-983-8242

Munson Medical Center
[3A,2G] Traverse City
Deborah Maas Francis, PT
Kari Jo Speckman, PT 231-935-8600

MINNESOTA

HealthEast Vascular Ctr - Lymphedema Program [1S, 1*, 1♦] Maplewood
Sandra K. Rosenberg, MD 651-232-2550

Courage Kenny Rehabilitation Institute Lymphedema Program
[3A,26G,1N,4S,11♦] Minneapolis
Nancy A. Hutchison, MD,CLT-LANA
Monica Heinen, PT, CLT-LANA 612-262-7900

Fairview Edema Treatment Ctrs
[9A,3G,4N,2S,1V,6♦] Minneapolis & Statewide
Lisa Karrow, PT www.fairview.org

Mayo Clinic – Lymphedema Ctr
[6A,4G,3N,7♦] Rochester
Andrea Cheville, MD
Jenny Bradt, PT,CLT-LANA 507-266-8721

MISSOURI

Ellis Fischel Cancer Rehab Center
[1N] Columbia
Genevieve Perso, PT,CLT,ALT
Karen Wingert, DPT,CLT 573-882-8445

Freeman Lymphedema Clinic
[1A, 1G, 2N, 1*] Joplin
Laura Linville, OTR/L 417-347-3737

Truman Medical Centers- Hospital Hill [3N,2♦] Kansas City
Karen Bock, PT, CWS, CLT-LANA
816-404-4325

Missouri Baptist Medical Center Outpatient Rehabilitation
[1G, 8N] St. Louis
Mary Maranzana, OT,CLT 314-996-3500

Cox Health System
[7G,1N,1A,3♦] Springfield
Jan Weiss, DHS, PT 417-269-5500
Alice Cornelison, PTA 417-269-5167

MISSISSIPPI

Baptist Lymphedema Clinic
[2A,1♦] Jackson
Ginger Stover PT,DPT,CLT
Caroline O’Cain OT, CLT 601-974-6243

NEVADA

Lymphatic Therapy
[2A,1G,1N,1V,1♦] Las Vegas
Joanne M. Matz OT, CLT
Shelley Bolor OT, CLT 702-367-6015

NEW HAMPSHIRE

Southern New Hampshire Rehab Ctr [1A,3K] Nashua
Amanda McCann, PT,CLT 603-577-8400

NEW JERSEY

CentraState Medical Center
[2G,6N,3♦] Freehold
Marinelle Japzon, PT,CLT-LANA 732-294-2700
732-637-6316

Barnabas Health Ambulatory Care Center LE Program
[2A,1N,1G] Livingston
Rita Loew, OTR/L, CLT-LANA 973-322-7293

Atlantic Rehabilitation Institute
[2G, 2N, 2 LANA] Morristown
Kathryn Ryans, PT, CLT-LANA
Jean Paluck, PT 973-971-4429

Wyatt Rehabilitation – Physical Therapy & Lymphedema Services
[1G,2N,2♦] West Long Branch
Tracey Podolsky, MPT,CLT-LANA
Kristy Blair, DPT,CLT-LANA 732-222-8556

NEW YORK

Delmar Physical Therapy & Lymphedema Treatment Ctr
[1V] Albany
Michele N. Keleher, MS,PT,CLT
518-439-1485

St. Peters Physical Therapy & Fitness [2A,1G,3♦] Albany
Heather Carangelo, PT, CLT-LANA
Mary B. Ryan, PTA, CLT-LANA 518-475-1818

Stony Brook University Hospital
[2LL,2N] East Setauket
Candiano Rienzie, DPT 631-444-4240

Gold Standard Physical Therapy [1A,1♦] New York City
Sandi Davis, PT,CLT-LANA 212-481-4022

NYU Langone Medical Center/Rusk Rehabilitation
[1A,1N,1V,2♦] New York City
Laurie Kilmartin, PT, DPT, WCS, CLT-LANA
Olga Kalandova PT, MS 212-263-5601

Memorial Sloan-Kettering Cancer Center [1A, 16N, 2♦] New York City
Ting-Ting Kuo, PT,DPT,WCS,CLT
646-888-1900

ShechterCare [1G] New York City
Cynthia J. Shechter, MA,OTR/L,CIMT,CLT-UE
212-421-1969

John T. Mather Memorial Hospital - Lymphedema Treatment Cent
[6G,3N,3♦] Port Jefferson
Lisa Malcomson, DPT 631-686-7648

**Lymphedema Therapy of Long Island
A Division of ProHEALTHCare**
[3B,2C,2*,2♦] Woodbury
Bonnie Lasinski, MA,PT,CLT-LANA 516-364-2200

NORTH CAROLINA

Carolinas Rehab–Main
[1A,2V,2♦] Charlotte
Vishwa Raj, MD
Elizabeth Koenig, OTR/L,CLT-LANA 704-355-0239

**Cone Health Outpatient Rehab
At Guilford College**
[1G, 3N] Greensboro
Marti Smith, PT
Donna Salisbury, PT,CLT 336-271-4940

**Frye Regional Medical Center -
Outpatient Lymphedema Service**
[3A] Hickory
Tennisha Mitchell OTR/L,CLT
Deanna Foster OTR/L,CLT 828-315-3186

**Caldwell Memorial Hospital Outpatient
Rehabilitation Services [2A]** Lenoir
Angela Smith, MS, OTR/L
Sandy Cannon, OTA,CLT 828-757-6226

OHIO

**Lymphedema Center at UH Geauga
Medical Center [2N]** Chardon
Dotti A. Thompson, MOT,OTR/L,CLT
Allison Evans, OTR/L, CLT 440-214-3100
440-285-6889

Cleveland Clinic Vascular Medicine
[3A, 1N] Cleveland
Leslie Gilbert, MD
Douglas Joseph, DO 216-444-5710

MetroHealth Medical Center
[2N] Cleveland
Mary Vargo, MD 216-778-3397

**The Stefanie Spielman
Comprehensive Breast Center**
[6A,1G,1N,1*,4♦] Columbus
Karen Hock,PT,MS,CLT-LANA 614-293-0043

Lima Memorial Health System
[1N] Lima
Roberta Keenan, OTR/L 419-226-5045
or 419-998-4704

TuDor Physical Therapy Centers
[2A,1T,1G] Youngstown
Gail DeMartino, PTA,CLT
Laura Dye, PT,CLT 330-799-1680

OREGON

**Healing Spirit Integrative Health
Center [4N]** Eugene
Carma Douglas, RN, CLT 541-683-1125

Rogue Regional Medical Center
[3A,1G,4♦] Medford
Janette Cariad, PT, CLT-LANA
Connie Miller, PT,CLT-LANA 541-789-4255

**New Leaf Physical & Massage
Therapy, LLC**
[3G,3♦] Portland
Chelsea Ana French, LMT
Mary Gramling, PT,CLT-LANA 503-318-7954

Providence Health System
[1A,1G,1N,3♦] Portland
Barbara E. Nicholson, PT, CLT-LANA
Tracy Hulleman, PT, CLT-LANA 503-216-1822
503-215-0264

PENNSYLVANIA

Centers for Rehab Services
[13G,1N,7♦] Cranberry Twp
Lisa Mager, MPT,CLT-LANA 724-742-9770

**Doylestown Hospital Physical
Therapy [4N,3♦]** Doylestown
Mona Dunlap, PT, MSPT,CLT-LANA
Morgan Murphy, DPT 215-345-2892

**Keystone Physical Therapy- Erie
South [1G,1N]** Erie
Elizabeth Darling, DPT,CLT,ATC,OCS
Amanda Scully, PT 814-860-7816

St. Mary Medical Center
[2G,5N,1♦] Langhorne
Brigette DiMarino, MS,OTR/L,CLT
Laura Puglisi, MOTR/L,CLT 215-710-2424

**Pinnacle Health Physical Therapy
of Camp Hill [2I,1N,2♦]** Lemoyne
Donna Kubik, PTA, CLT-LANA
April Evanitsky, PTA,CLT-LANA,LMT 717-214-3688

Fox Chase Cancer Ctr
[1G,3N,1*,3♦] Philadelphia
Wilma Morgan-Hazelwood, OTR/L,CLT-LANA
Janice G Buhler, MS,PT, CLT-LANA
215-728-2592 or 215-728-3469

Penn Therapy and Fitness
[4G,1V,4N,1LL,7♦] Philadelphia/
Radner/Cherry Hill, NJ
Joy C. Cohn, PT,CLT-LANA
Nicole Dugan, PT, CLT-LANA 215-662-4242

**Allegheny Chesapeake Physical
Therapy [2G,1T]** Pittsburgh
Suzanne Cavanaugh, DMPT,CLT
Kristen Carlin, PT 412-661-0400

**Schuylkill Rehabilitation
Center [2*]** Pottsville
Patricia Gregas, OTR/L
Lynn Kamarousky, OTR/L 570-621-9500

SOUTH CAROLINA

Hilton Head Occupational Therapy
[1A,1♦] Bluffton
Madeline Chatlain, OTR/L,CLT-LANA
843-757-9292

**Palmetto Health Baptist
Lymphedema Treatment Ctr**
[1G,1N,1V,3♦] Columbia
Kel Jansen, OTR/L,CLT
Marie McGowan, PT,CLT-LANA 803-296-5486

**McLeod Health Lymphedema
Treatment Ctr [4A,1LL,2♦]** Florence
Ashley Atkinson, OTR/L,CLT-LANA,WCC
843-777-2043

TENNESSEE

Siskin Hospital Lympehema Clinic
[4A] Chattanooga
Kathy Clark, PTA,CLT 423-634-1200

Marino Therapy Centers
[2A,1C,2♦] Knoxville
Kathleen Westbrook, PT,CLT-LANA
Dianne Kerr PT, CLT-LANA 865-690-2671
or 865-558-6484

**Vanderbilt Lymphedema Therapy
Clinic [3A,1*,2♦]** Nashville
Jadranko Franjic, PT,CLT-LANA 615-343-7400 x1
Adrien Mackenzie, PTA,CLT,LMT 615-343-7400 x2

TEXAS

North Cypress Medical Center
[1G,3N] Cypress
Gretchen Sprouse, OTR/L, CLT
Rene Schuster, OTR/L, CLT 832-912-3791

Texas Health Resources Dallas
[6V,1♦] Dallas
Wendy O'Rear, PT,CLT 214-345-5204
Vail Fassett OT,CLT-LANA 214-345-7133

**Memorial Hermann Lymphedema
Center [3A,2N,3V,4♦]** Houston
Laura M. Braxton, OTR,MSOT,CLT
Kirk Cowardbéy, OTD,MOT,OTR,CLT
713-704-5900

Covenant Hand Therapy [2A] Plano
Gail Blom, MA,OTR,CLT,CHT 972-599-9594

PVA Lymphedema Center
[1A,1V,1♦] San Antonio
Rachel McCabe OTR/L,CLT
Susan Harrelson, RMT,CLT-LANA
210-237-4464

**H.O.P.E (Helping Out People with
Edema) Lymphedema Treatment
Ctr, PLLC [1G,1V]** Sugar Land
Tammy Sweed, RMT, MLDT
Robin Poe, RN,MLDT 281-242-5807

UTAH

**Intermountain Lymphedema
Clinic [1A,1N,1V,2♦]** Murray
Jennifer Girtten, OTR/L,CLT-LANA 801-507-3967
Sarah Anderson, OTR/L,CLT-LANA 801-507-3966

6 ~ Resource Guide

VIRGINIA

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[G/◆]
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Please note that treatment facilities or businesses that offer Support Groups must be an active NLN Affiliate to qualify for inclusion in this listing.

For more information please visit www.lymphnet.org/patients/supportGroup.htm

Lymphedema Surgery: The Lymphedema Therapist's Perspective

By: Julie M. Soderberg, MPT, ATC, CSCS, CLT-LANA
Providence Little Company of Mary Medical Center, Torrance, CA



Over the fifteen years that I have been practicing as a physical therapist specializing in the treatment of lymphedema, I have seen many different patients present with all four stages of this complex disease process. In many instances, treatment has been long, difficult, and demanding for both patient and therapist. Patients have often expressed hope for a cure during their lifetime. They longed for the day they could wake up in the morning without having to think about what they have to do that day to keep their lymphedema leg or arm stable.

We still have no definitive “cure” for lymphedema. However, surgical options now exist that have significantly improved the management of lymphedema.

The three best known surgical options for lymphedema currently available are the suction assisted protein lipectomy (SAPL), lymphaticovenous anastomosis (LVA), and vascularized lymph node transfer (VLNT) procedures. For more than five years, I have worked with a surgeon who performs these three procedures.

Before being considered a candidate for lymphedema surgery, patients must first undergo lymphedema therapy performed by their local qualified lymphedema therapist. Usually, this means at least one course of complete decongestive therapy (CDT) followed by continued therapy sessions and compression garments. Patients who fail to respond adequately to CDT may be candidates for lymphedema surgery.

Patient selection for each of the procedures is paramount. Patients

tend to fall into two categories: those with volume excess which is predominantly solid, and those whose volume excess is mostly fluid. The first group of patients has lymphedema that is predominantly solid and corresponds to Lymphedema Stages two to three. They do not respond favorably to conservative treatment, and quite often have a history of either not wearing compression garments or using ill-fitting garments over the years. They may also have had poor access to or compliance with lymphedema therapy. These patients respond very well to the SAPL procedure, which removes excess solids and fat.

After the SAPL procedure, most patients can expect the size of their affected arm or leg to approach the size of their opposite, unaffected arm or leg. The results can be impressive, and witnessing patients returning to “ground zero” after this procedure is extremely rewarding. After the SAPL procedure and recovery, seeing pictures of patients wearing a form-fitting shirt, skinny jeans, or calf-high boots for the first time since developing lymphedema has been unforgettable.

The lymphedema therapy required before and after the SAPL procedure is intense and requires an experienced lymphedema therapist with special training relating to this procedure. These patients take much more of my time and effort to treat than other lymphedema surgery patients?. However, this extra attention is essential because patients will experience poor post-surgery results if therapy is not performed properly. Preoperative fitting with custom garments is the first step. The opposite, unaffected arm or leg is used as a template to order

the custom, flat knit postoperative garments required after surgery. Depending on the patient, compression garments or short stretch bandages are placed in the operating room at the end of the procedure to minimize postoperative swelling.

After the SAPL procedure, these patients require close observation by their local lymphedema therapist to follow their progress and make adjustments to their garments as the lymphedema swelling subsides. Collaboration between the surgical lymphedema therapist, such as myself, and the patient's home lymphedema therapist is imperative, because the patient returns to their own local therapist for continued treatment during their recovery.

While the SAPL procedure is successful in removing the excess lymphedema solids, it does not prevent new accumulation of excess lymph fluid. Therefore, continuous compression garments are mandatory to prevent reaccumulation of lymph fluids. A patient who is not willing to wear compression 24/7 would not be considered a candidate for this procedure. Therefore, I require my patients to be completely comfortable with compression garment use before referring them for a SAPL procedure.

The second group of lymphedema patients have mostly fluid, rather than solid, volume excess in the affected arm or leg. These patients tend to present earlier in the disease process in Lymphedema Stages 0 or 1, initially tend to respond better to conservative therapy, but require continued garment use and therapy to maintain their improvements. They can be candidates

for the LVA and/or the VLNT procedure, which are physiologic procedures that can be effective in removing excess lymph fluid. These procedures may serve as a second stage after the SAPL procedure to help control the residual fluid accumulation and decrease dependence on long-term compression garment use. In short, the best candidates for the LVA or the VLNT procedures have a fluid-predominant, low-volume excess presentation for the optimum result.

I have found that patients tend to have a very favorable result with markedly less dorsum hand involvement after receiving the VLNT procedure. Because we have found this procedure to be effective at preventing progression of lymphedema, I have suggested the VLNT procedure to patients considering breast reconstruction who have minor symptoms or are at high risk for developing lymphedema since the VLNT procedure can be combined with a deep inferior epigastric perforator (DIEP) flap breast reconstruction procedure.

After the LVA or the VLNT procedures, patients typically spend less

time in therapy and less time in compression than before surgery. Some patients after the LVA or the VLNT procedures can be out of compression for a certain number of hours a day. For example, patients with arm involvement who have had the VLNT procedure can be out of compression for 7 to 10 hours a day. Some patients have been able to cease wearing the glove or gauntlet altogether. Again, patient selection is very important, as I have found that VLNT and LVA tend not to be effective in treating the excess solids in chronic lymphedema that are better treated with SAPL.

While surgical results can be impressive, I do not consider surgery to be the cure. Regardless of which surgery is performed, it is important for patients to continue to receive guidance from their certified lymphedema therapist (CLT). Consultation with a CLT experienced with measuring custom garments is crucial to assist the patient preoperatively and during their postoperative care. Patients are encouraged to perform self-MLD daily after surgery to encourage improved lymphatic flow.

I also advise patients that they should choose a lymphedema surgeon who is not only Board Certified in Plastic Surgery and who is experienced with performing the procedures, but who also understands the importance of lymphedema therapy as an integral part of the patient's preoperative evaluation and postoperative care. For example, just because a plastic surgeon is able to perform cosmetic liposuction does not mean that they will be able to achieve the consistent and dramatic results seen with the SAPL surgery. My experience confirms that a lymphedema surgeon who is properly trained in the lymphedema procedure is essential for a successful outcome and to minimize surgical risk.

Ultimately, it takes teamwork among the lymphedema surgeon, trained lymphedema therapist, and the patient to achieve the most successful outcome. When employed as part of an integrated treatment system for properly selected patients, lymphedema surgery can be an excellent treatment tool.

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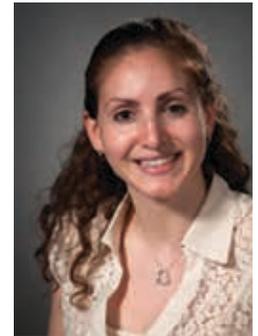
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Nutrition

Grocery GPS: Navigating Your Way to Delicious Healthy Foods

By: Hillary Sachs, MS, RD, CSO, CDN
North Shore-LIJ's Cancer Institute, Great Neck, NY



Meals to Heal

Walking into a grocery store, even with a specific shopping list, can be overwhelming - even for the most savvy shopper. "How do I tell that this avocado is good?; how do I choose a good watermelon?; which of these breads are best to buy?" are just some of the hundreds of thoughts that could turn this commonplace chore into confusion overload. The goal of this article is to address these questions and general food shopping confusion and to help you choose the most healthful, anti-inflammatory foods to help manage your lymphedema.

Why even bother preparing my own food versus eat out you may be thinking? Here are my top five reasons why doing your own shopping and cooking is more healthful:

1. Pocket more \$
 - If two people are eating out for 3 meals per day with an average of \$8 per meal, this will amount to \$48 per day and \$336 per week! This could buy you the most expensive, organic foods in the grocery store with money still left over!
2. Save on your calorie budget
 - When many food service establishments prepare foods, their primary goal is taste and to get you to come back. Thus, they may load up on salt, sugar and oils. Make the same dish at home and likely you will be saving hundreds of calories without even trying! In addition, you may be more tempted to supersize

your order or add on fries if you are out vs eating at home

3. Know the quality of food you are getting and thus improve your health
 - When eating out, you don't know where the food came from or the quality of the food. Is it organic, is it non-GMO, etc.? You have the control when you are doing the shopping
4. Teaches and supports good life skills
 - Cooking teaches more than just that. It teaches skills including planning ahead and following precise directions. It is a great opportunity for people to get creative and use a part of their minds that they may not use in everyday life. Get everyone in the family to participate and submit and /or cook a recipe!
5. Creates more quality family time
 - Sitting around a dinner table is a great time to talk about everyday things that may not come up in the hustle bustle of rushing around and eating on the go.

General Guidelines Aisle by Aisle:

Before you go:

- Do not go hungry
- Bring a list
- Shop the perimeter; this is where the freshest foods are
- Look for ingredient lists that are simple and easy to understand
- Make sure you are stocked with flavorful herbs and spices, low

sodium broths, frozen fruits and vegetables for when/if you run out of fresh

Produce checklist:

- Look for skew numbers that start with 9. This means that it is organic. If it starts with 3 or 4 soak in water with 1 part vinegar, 1 part water to remove pesticide residue
- Where does the food come from? Is it grown in the US? Remember, the farther a food travels, the more time for nutrient content to decline. Locally grown and in season is always best!
- Get a variety of colors. Each color has a different health benefit!
 - *Purchasing pointers:*
 - Avocados/pears are ripe when they "give" a little when you squeeze them. If they are not ripe, bring it home and let it sit on the counter until it is
 - You can tell a watermelon is ripe if you bang on it and it sounds hollow like a drum
 - You can tell cantaloupe is ripe if it has a slightly sweet smell
 - Make sure your produce is free of mold, is dry and not wrinkled
 - If your produce starts to go bad, like apples, cut off the blemishes and bake it!

Dairy/dairy alternatives checklist:

- Read the ingredients; when possible, minimize added sugars or ingredients you may not understand
- Look for hormone/antibiotic free dairy (organic is automatically these things)
- Look for low fat as opposed to non-fat and full fat. You will increase your satiety and absorb more of the

- calcium, vitamin A and D this way
- Look out for added sugars. Dairy will always contain some natural sugar because lactose is considered a sugar. 1 cup of milk has about 12 grams of sugar naturally. Try not to much exceed this limit

Meat/poultry/eggs checklist:

- Look for hormone/antibiotic free (organic is automatically these things)
- Grass-fed beef; this contains more anti-inflammatory fats compared with conventional, corn fed
- Free range, pasture raised
 - *Purchasing pointers:*
 - These can often be more expensive: use as a side dish rather than the main part of your plate
 - Look for frozen; this is often more affordable

Seafood checklist:

- Where does the fish come from? Choose local fish if possible. Fish from other countries may be more contaminated
- If using canned fish, try to find those that are BPA free or in a pouch as an alternative
- Minimize consumption of fish high in mercury
- Use a website such as seafoodwatch.org to choose fish choices low in mercury and high in anti-inflammatory omega-3 fat.
 - Includes wild salmon (usually cheaper if frozen), trout, haddock and mussels
 - Wild salmon, tuna, and mackerel are some of the highest in omega-3 fat.

Grains/breads checklist:

- Avoid refined or enriched grains in the ingredient list
- Avoid sugar/high fructose corn syrup

- in the ingredient list
- Look for simple, understandable ingredients
- Look at fiber content per serving: you want it to be at least 3 grams or more per serving
- Try other kinds of grains: amaranth, teff, quinoa, buckwheat, millet, sprouted/Ezekiel bread
- Trying other grains can offer variety in texture, flavor, and beneficial nutrients
- Some breads, like Ezekiel, offer more bioavailable nutrients and have nutrient-rich ingredient list

Beverage checklist:

- Are there artificial colors or flavors?
- Is it possible to avoid plastic containers for this product?
- How much added sugars are in the product? (Other names for sugar include malt, cane syrup, molasses, etc.)
- Choose herbal teas. You can add ice and add 1 tsp of honey or mint leaves for a delicious iced tea
- Choose seltzer as a calorie free thirst quencher
- Flavor water with fresh or frozen fruit

Condiments/sauces checklist:

- Look for simple ingredients. You want to understand what foods you are eating!
- Use products like hummus, salsa, guacamole, tomato sauce, nut butters, herbs/spices and olive/coconut oil
- Avoid added salt, sugar
- Make your own ketchup, salad dressing
 - Mix lemon juice, olive oil, basil and oregano for a tasty/light dressing
 - Mix tomato paste, apple cider vinegar, honey, garlic powder and onion powder

What does it mean? Deciphering the labels

- *All natural:* does not contain preservatives, colors, additives. Not an indicator of antibiotics or hormones
- *Free range:* animals have access to outdoors but do not necessarily go outdoors
- *Organic:* no pesticides, antibiotics or hormones. Made with 95% organic ingredients unless 100% is specified
- *Multigrain/whole grain:* made in part with whole grains but product can still contain white flours. Read ingredient lists!
- *No sugar added/sugar free:* does not mean calorie or carbohydrate free. May contain artificial sweeteners, many of which result in stomach upset
- *Reduced sodium:* 25% less than original product but product itself may still be high in sodium; 120-140 mg or less is considered low; 480mg or more is considered high
- *Low fat:* 3 grams or less per serving
- *Trans fat free:* <0.5 g trans fat per serving; make sure there are no hydrogenated oils in the ingredient list

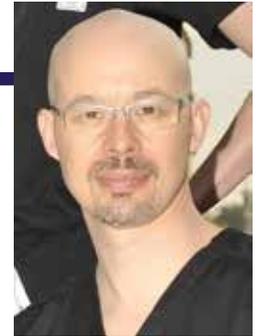
By using this Grocery GPS to navigate the grocery store, you will be able to choose healthy, minimally processed foods. These foods will not only help you to improve your overall health, but can also help you to reduce inflammation and maximize your nutrition to help you best manage your lymphedema and other chronic conditions. After all, “we are what we eat” so the better we treat our bodies, the the better our bodies will take care of us!

hillarysachsnutrition@gmail.com
www.hillarysachsnutrition.com

Hillary Sachs, MS, RD, CSO, CDN is a board certified oncology dietitian with a private practice and working at Meals to Heal, LLC. She is passionate about the relationship that proper nutrition has on general health and quality of life.



By: Richard Klein, MD, MPH
UF Health Cancer Center, Orlando Florida



Q: What is a vascularized lymph node transfer surgery?

A: Vascularized Lymph Node Transfer (VLNT) surgery is a microvascular reconstructive procedure involving the harvest of healthy lymph nodes and vessels, in the form of a small free flap, from a viable donor site and transferring it to the lymphedema affected limb. Specially trained lymphedema surgeons employ microsurgical techniques to transfer an estimated 5 to 8 lymph nodes into the affected body part.

Q: Does VLNT surgery work?

A: Yes. Over time, these vascularized lymph nodes will grow new lymphatic channels that can bridge the gap between the blocked lymphatic channels and the unblocked ones. The lymph nodes can also directly drain excess lymphatic fluid. In some cases, such as a lymph node transfer to the axilla (armpit), tight and obstructing scar can be removed and replaced with the healthy lymph node-containing tissue. This can further improve drainage.

Q: Who is an ideal candidate for VLNT surgery?

A: Lymphedema tends to cause the lymphatic system to break down increasingly over time. Therefore, an ideal candidate for VLNT is someone who has recently developed lymphedema. The sooner we are able to address the lymphedema, the better the outcome we will have with the surgery.

Q: What kind of time commitment is involved before and after VLNT surgery?

A: Before surgery, lymphedema therapy is very important to reduce to fluid volume excess as much as possible. For most patients, this means at least one course of Complete Decongestive Therapy (CDT) prior to surgery with continued therapy as needed up to the time of surgery. After surgery, therapy may begin immediately or may not be recommended to begin for several weeks, depending on the details of

the procedure and the protocol of the surgeon. Eventually, the transferred lymph nodes may significantly improve the effectiveness of therapy and reduce the amount of therapy required.

Q: How long do conservative measures (i.e. manual lymphatic drainage, garments, bandaging) need to be tried first?

A: Lymphedema therapy is an important part of achieving the best results possible with VLNT or other lymphedema surgeries. The type and length of therapy will vary between individuals. It would be reasonable to expect at least six or more weeks of conservative therapy prior to surgery for best results.

Q: If I've had lymphedema for more than 10 years am I still a candidate?

A: Yes, patients could be considered for VLNT surgery if their lymphedema excess volume still contains a significant fluid component. Patients with chronic lymphedema characterized by large amounts of excess solid may be better treated by removal of these solids first with a different procedure, called suction assisted protein lipectomy (SAPL) surgery. A consultation with a lymphedema surgeon is recommended to make that determination.

Q: What are the expected outcomes?

A: Patients can expect to experience gradual results, such as reduction in swelling, tightness, and heaviness, within a few months of VLNT surgery. While it may take up to 18 months to determine the complete result, many patients report symptom improvements within a few weeks of the VLNT. These factors depend heavily on the cause and severity of the lymphedema.

Q: What credentials should my surgeon have?

A: At minimum, lymphedema surgeons performing VLNT surgery should have significant previous training and experience with microsurgery and

lymph node transfer procedures. They should have a close working relationship with a certified lymphedema therapist. They should also be willing and able to take the time to answer any questions regarding their experience and their approach to lymphatic surgery.

Q: How will this surgery improve my quality of life?

A: The vast majority of patients report reduction in swelling, tightness, and weight of the affected limb with improved range of motion. Reduction in pain, risk of infection, and return to normal activities are some of the most notable quality of life benefits reported by patients.

Q: How long does VLNT surgery take?

A: The surgery itself takes about two to eight hours under general anesthesia. One of the goals of the microvascular surgical team is to minimize a patient's time under anesthesia to aid in a faster recovery.

Q: How long will the hospital stay be?

A: The average hospital stay is one night.

Q: How soon after surgery can I travel?

A: There will have a drain placed after surgery for the purpose of reducing fluid accumulation at the surgical site. The drain is generally removed from 1-3 weeks after surgery depending on the amount of drainage. Depending on the patient and the physician, patients can often fly home after 1 week.

Richard.klein@orlandohealth.com

PATIENT PERSPECTIVE



By: JoAnne DaCosta, Cape Cod, MA

I am a 7-year breast cancer survivor. My journey with breast cancer and lymphedema began when I noticed an indentation on my left breast while towel drying my hair in a mirror. I was treated with a left mastectomy, axillary dissection surgery, aggressive chemotherapy and radiation for stage 3 breast cancer.

Eight months after receiving treatment for breast cancer my left arm

began to swell. My primary care doctor stated, "There is nothing we can do for that." Being a nurse, I could not believe doctors could not do anything for my arm.

My oncologist suggested lymphedema therapy. I was treated with Complete Decongestive Therapy (CDT) for several months with good effect. A year later after another cancer scare, I opted to have a prophylactic right mastectomy. For some reason after this surgery the lymphedema became more difficult to treat with CDT. I then experienced a frozen shoulder with an enormous amount of pain and discomfort. My arm was not draining, I had cording, the arm had a lumpy texture and it seemed like the fluid was seep-

ing out the pores. I also experienced a heaviness, tingling and numbness. The lymph fluid was becoming stagnant.

My first bout of cellulitis began with a cuticle skin tear on the thumb of my affected arm. At the time I was seeing my certified lymphedema therapist (CLT) twice weekly, bandaging and using my compression sleeve. When my thumb became sore, my arm painful and hot within 24 hours of the skin tear, I took my bandages off and saw that my arm was bright red, hot and shiny. I had a fever and every bone in my body ached. I was scared and my CLT told me to get treatment right away. That incident began my first hospitalization of many hospitalizations for cellulitis.



Arms Pre-Operation



Arms 28 months Post-Operation

It was scary to know just how fast cellulitis can travel and I realized that I did not want to live my life in fear of cellulitis returning. Returning to my CLT and having CDT 2 times per week, bandaging and wearing my compression sleeve were not enough. I can take some responsibility by not always being consistent with my sleeve. It was really cumbersome under my clothing. I had to wear clothes several sizes bigger than my size and I always felt awkward and uncomfortable. At work it was difficult because I worried about infection and injury all the

time and patients would constantly ask "What is wrong with your arm?"

I had cellulitis several other times and I became so frustrated and was unable and unwilling to continue living my life this way. I had coped with the side effects from chemotherapy and radiation but my greatest hurdle was living with lymphedema and the severity of life threatening side effects that may occur.

My CLT, Brenna Quinn, educated me on the surgical treatments that were being used and their effectiveness on lymphedema patients. In researching my options, I elected to consult Dr. Granzow whom my CLT knew and respected as a great plastic surgeon with a passion for helping breast cancer survivors with lymphedema and breast reconstruction. My husband and I traveled across the country, from Cape Cod to L.A., making our trip a vacation and a medical consult for lymphedema. Dr. Granzow thoroughly explained the surgical procedures that could treat my stage of lymphedema. The first procedure I re-

ceived was a suction-assisted protein lipectomy (SAPL) of my left arm which removed the solids that had built up from having no drainage. After reducing my arm, wearing a compression sleeve and glove for a year, having my arm measured by my CLT periodically and continuing with CDT I was eligible for a lymph node transfer. Through this process I learned just how important a compression sleeve was. During the rehabilitation process after SAPL, my arm became progressively smaller and the compression garment needed to be altered to stay tight enough to keep my arm reduced.

My goal was to be free of a compression sleeve as much as possible. Dr. Granzow recommended the lymph node transfer surgery so that I would not need to wear it 24 hours a day. The option was to have that alone or in conjunction with deep inferior epigastric perforator (DIEP) breast reconstruction. After my daughter and I consulted with Dr. Granzow, I made my decision to have the DIEP with the lymph node transfer.

The combined DIEP reconstruction and lymph node transfer surgery from my groin to the axilla was one of the best decisions of my life. My arm looks normal again, I can wear clothes my own size, I feel healthier than I have in years and I celebrate 60 years of life this year as an 8-year breast cancer and lymphedema survivor. I only have to wear the sleeve about half the day, during the evenings and at night. I mentioned many times that I only needed a functional arm that was less susceptible to cellulitis. However, the truth is that having reconstructive surgery with SAPL surgery and then lymph node transfer surgery has changed my life. Today I am healthy and feel comfortable in my own skin. I want to thank Dr. Granzow, my CLT Julie Soderberg who works side by side with Dr. Granzow, and my CLT Brenna Quinn who has worked tirelessly and patiently with me for making this possible, especially after hearing from my first doctor that, "There is nothing we can do about that."

Email: Jdacosta6@hotmail.com

stop



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LSAP Alum Wins \$5,000

NLN Lymph Science Advocacy Program (LSAP) graduate and support group leader Becky Sharpe won the first-place prize of \$5,000 as part of Juzo's Keep Moving challenge. Congratulations, Becky!



LSAP Alum Honored by NORD

Sophia Hanson, LSAP 2014 alum, was honored by the National Organization for Rare Disorders (NORD) as part of the 2015 Portraits of Courage celebration on May 19, 2015, in Washington, D.C. Sophia was among 10 honorees who shared their powerful, inspiring stories. See www.rarediseases.org/2015-portraits-of-courage-honoree-sophia-hanson/



Lymphedema Treatment Act (LTA) Update

The Lymphedema Treatment Act is off to a strong start this congressional session with over 100 House cosponsors already. All of these cosponsors are the result of constituent contact, from people just like you!

Cosponsors are one of the key factors in deciding which bills are moved forward in the legislative process and passed into law. Continuing to increase our cosponsor count is very important, and your help is critical.

Constituent contact is what matters most. Your Representative's office needs to hear from you, possibly multiple times, so don't be daunted if you receive a noncommittal form letter reply at first. Persistence makes the difference, and calling after emailing is especially important.

Visit our website to see if your Representative is a cosponsor, then write and call his or her office using the

advocacy tools under the How You Can Help menu. Our new Phone Contact Form will provide you with the number to call, person to ask for, and talking points.

Please take action today!
LymphedemaTreatmentAct.org



LANA Updates

TIME TO RECERTIFY?

LANA therapists are to recertify every six (6) years. This year CLT-LANA therapists who **certified** or recertified in 2009 are up for recertification. Applications are on-line and are due Dec. 31, of this year. You may check your certification status on line through your individual login on the LANA website.

Interested in becoming a LANA Board of Director or on the LANA Examination Committee?

Applications are now available on-line to join the LANA Board of Directors or to become a member of the LANA Exam Committee. We would love to hear from you! For questions on either, please contact Katina Kirby at admin@clt-lana.org.

Candidates wishing to take the LANA Certification Exam may apply take the exam any time during the year. Results will be given immediately for those taking a computer based test. Please visit our website for details: www.clt-lana.org Applications may be emailed to admin@clt-lana.org or mailed to: **LANA, P.O. Box 16183, St. Louis MO 63105.**

Stop by and visit LANA's booth at the 25th World Congress of Lymphology in San Francisco this September.

For any questions or concerns, please contact LANA at admin@clt-lana.org or call 773-756-8971.

Katina Kirby, MS, OTR/L, CLT-LANA

Executive Director, LANA



Call for Support Groups

If you are interested in starting a lymphedema support group in your area or need resources for your existing group, please reach out to the NLN today! We are happy to assist with information, materials and other timely updates. Support group applications are available at www.lymphnet.org/node/1050, or please contact Sam Roth at NLN@lymphnet.org or 415-908-3681. We look forward to hearing from you!



Lymphedema Patient Online Support Community

The NLN's online support community through inspire.com has been taking off with new conversations daily! It is a great place to connect with other patients, caregivers, and even medical professionals in the lymphedema community.

[Inspire.com](http://inspire.com) is free for everyone and we hope that you will take part and help us grow! lymphnet.inspire.com/



LymphLink

Call for Authors!

LymphLink welcomes author-initiated papers or case studies that are relevant to patient care and clinical practice. Please email a brief abstract to Saskia Thiadens at saskiat@lymphnet.org. If the abstract is appropriate for LymphLink, we will contact you for full paper submission.





Support the NLN

Do you shop on Amazon? Do you want to support the NLN? You can now do both thanks to Amazon Smile. When shopping on Amazon, simply sign in through smile.amazon.com (your log in information and shopping cart/wish lists will remain the same!) and select the NLN as your preferred charity.

Amazon Smile will donate .5% of the purchase price of thousands of eligible items to the NLN, which will help us continue to educate patients and health care professionals alike.

Another great way to support the NLN is to donate your old car.

A charitable donation to National Lymphedema Network via an old car makes a huge difference. The “old clunker” will quickly convert into support for patients in need through the Marilyn Westbrook Garment Fund, educational materials distributed to cancer centers, and outreach to those seeking substantive information about this difficult disease. All the logistics and paperwork will be handled for you. This is a very easy way to support NLN’s work on behalf of patients, just visit the NLN website at www.lymphnet.org and click on the “Donate” page or follow this link - <http://www.lymphnet.org/ways-to-help>



Lymphedema Seminars

Networking & Educational Seminars for Lymphedema Therapists

*TUCSON, AZ (Oro Valley Hospital November 6-8, 2015 (10 contact hours)

PLUS OPTIONAL PRE-SEMINAR WORKSHOP

“Fibrosis Treatment: Reduce Pain & Lymphedema, Improve Function” with Karen Ashforth, MS, OTR, CHT, CLT-LANA
Friday, November 6, 2015: 1:30-5:30 pm (4 contact hours)

SAVE THESE DATES for 2016:

ORLANDO, FL	JAN 29-31
DALLAS, TX	FEB 19-21
CHARLOTTE, NC	MAR 4-6
PHOENIX, AZ	APR 1-3
INDIANAPOLIS, IN	MAY 13-15
ST LOUIS, MO	JUNE 3-5
BALTIMORE, MD	OCT 7-9
PALM SPRINGS, CA	NOV 4-6

Visit www.lymphseminars.com for further information, to either fill out or download a Registration Form for Tucson, and for our 2016 proposed schedule of seminars, or call 805.772.3560.



Future Meetings & Events

Save The Date for NORD’s Annual Rare Diseases and Orphan Products Breakthrough Summit

October 21-22, 2015 at the Crystal City Marriott in Arlington, VA.

As a proud member organization of NORD, the NLN will be in attendance representing lymphedema at this Summit - the largest and most meaningful multi-stakeholder event of its kind – being held in Arlington, VA on October 21 and 22. The 2015 Breakthrough Summit convenes the top leaders from the FDA, NIH, pharma and biotech industries, as well as patients, caregivers and patient organizations. For more information, or to register for this event, please visit NORD’s website at <http://rarediseases.org/event/rare-diseases-orphan-products-breakthrough-summit/>



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President’s Message

Continued from page 2

After thoughtful deliberation, she decided to undergo first stage SAPL surgery followed by second stage breast reconstruction and lymph node transfer 15 months later. Today her arm is “normal” and she is living life to the fullest. The above cases are encouraging. Careful patient selection and treatment by experienced plastic surgeons should insure that we will continue to see progress in this population. A special thank you to Dr. Granzow and his team for sharing their great interest and experience.

2015 was an eventful year for LE nationwide, increased interest in LE among the various disciplines. The number of CLT’s and affiliated clinics is growing, and interest in the lymphatic system and related disorders continues to grow in the scientific world. The Lymphedema Advocacy Group has doubled our supporters of HR-1608. Please continue to write your state representatives. Sample letters of support can be found at LymphedemaTreatmentAct.org.

Lastly, I would like to applaud the NLN Medical Advisory Committee (MAC) and Research committee (RSC), a dedicated group of clinicians and researchers who volunteer their time to support this organization and its mission. I want to extend a very special thank you to Cathy Tuppo, MS, PT, CLT-LANA who chaired the committee for the last few years. Thank you, Cathy! We extend a warm welcome to our new MAC Chair - Jamie Wagner MD.

The 12th NLN International Conference is rapidly approaching. Registration opens October 15th and abstract submission opens January 1, 2016. See page 16.

The NLN Board of Directors and staff wishes you a peaceful holiday season. We look forward to continued collaboration and growth in the field of lymphology in your community and nationwide.

Respectfully,

Saskia R.J. Thiadens R.N.
Executive Director & Founder NLN
saskiat@lymphnet.org

Support Group Schedule

Support Groups: To list your upcoming events, please send us info to nlm@lymphnet.org

MISSION HILLS, CA

Lymphedema Support Group
3rd Thursday from 4 pm to 5 pm
818-496-1643

VENTURA, CA

Lymph Luminaries
3rd Tuesday, 12 pm to 1 pm
805-652-5459

AVENTURA, FL

Aventura Lymphedema Chat
2nd Tuesday
305-937-5802

FLEMING ISLAND, FL

Lymphedema Support Group
Start-up, call for information
904-269-9113

ROSWELL, GA

Lighthouse Lymphedema Network
4th Thursday of Sept., Oct.
770-442-1317

LOUISVILLE, KY

Norton Cancer Institute
Lymphedema Program
4th Wed Each Month, 6:30 pm - 7:30 pm
502-629-4062

BATON ROUGE, LA

Baton Rouge General
1st Tuesday, every other month
205-763-4243

SOUTH PORTLAND, ME

Lymphedema Support and Education Group
1st Wed of Sept., Nov., 12:00 pm
207-400-8520

LAS VEGAS, NV

Lymphedema Mavens
4th Wednesdays, 5:30 pm to 7:30 pm
702-860-2927

MANCHESTER, NH

Aventura Lymphedema Chat
1st Friday
603-641-6700

NEW YORK, NY

SHARE Lymphedema Support Group
Every other month
844-275-74273 (ASK-SHARE)

PORTLAND, OR

Legacy Cancer Services Lymphedema Support
2nd Tuesday 4 pm - 5:30 pm
503-413-7284

PROVIDENCE, RI

Program in Women's Oncology Lymphedema Support Group
1st Thursday of every month
401-274-1122

JEFFERSON CITY, TN

Lymphedema Awareness Network of East Tennessee
Tuesdays
865-607-3476

TYLER, TX

The Lymphedema Support Group of Greater East Texas
1st Wednesday of every month from 9am - 11am
903-740-1884

KENT, WA

Northwest Lymphedema Center
Saturday- Quarterly (call for dates)
206-575-7775

BELOIT, WI

Lymphomaniacs
Wednesdays every other month
608-364-2337



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MESSAGE FROM THE NLN BOARD CHAIR

By: Patricia Egan, MS, MBA, San Francisco, CA



The World Congress of Lymphology and Patient Summit have been a whirlwind of activity! With patients, therapists, researchers, doctors, nurses, and world-renown experts from more than 30 countries all together, the Congress and Summit have provided us with a wealth of new information about both lymphedema and lipedema. The exhibit hall has been teeming with activity as we see new products and services. Parents and patients shared some of their complex histories during the “Patient Clinic,” which a panel of clinical experts reviewed to provide insights and hope for many patients.

I am very glad to see so much advocacy and activism throughout the Congress and Summit. Alumni of the Lymph Science Advocacy Program (LSAP) have attended sessions in both the Congress and Summit. Dr. Julie Hanson, Legislative Affairs Chair and Lymphedema Advocacy Group Executive Committee member, conducted a briefing session about the new Avalere Health analysis of the Lymphedema Treatment Act, H.R. 1608, and updated the audience about the growing level of cosponsorship among members of the House of Representatives. People interested in becoming involved with their state teams had the opportunity to meet with Heather Ferguson and Patti Graybeal in the exhibit hall. NLN supports passage of the Lymphedema Treatment Act, and many LSAP alumni are involved at leadership levels.

Saskia Thiadens and I recently attended the West Coast Conference on Rare Disease Legislative Advocacy at the University of California San Francisco Medical Center. I thought that you might like to know more

about other advocacy work in which NLN is engaged. For over a decade, NLN has been an associate member of the National Organization of Rare Disorders (NORD), and NLN is cited as a resource for information about lymphedema, which is classified as a rare disease. <https://rarediseases.org/rare-diseases/hereditary-lymphedema/>

On July 10, the House of Representatives passed The 21st Century Cures Act, H.R. 6, which provides National Institutes for Health (NIH) funds for research and treatment of rare diseases such as lymphedema. Passage of this bill was considered a major achievement for the rare disease community, and a similar bill will need to be presented to the Senate. The EveryLife Foundation for Rare Diseases, www.everylifefoundation.org, provides a good deal of information about legislation related to rare diseases in a broad sense, if you would like additional information.

In the State of New York, Assembly Bill 230 is under consideration for the establishment of a grants program to support lymphedema and lymphatic diseases research. NLN supports this bill, and our Founder and Executive Director, Saskia Thiadens, wrote a compelling letter of endorsement to Governor Andrew Cuomo. You might like to know that Saskia was honored with a Legislative Resolution last June by the New York State Legislature in recognition of her many years of pioneering work on behalf of lymphedema patients through NLN. NLN members who reside in New York might well want to read more about this bill at <https://legiscan.com/NY/bill/A00230/2015>.

If you read NLN’s Team Inspire blog regularly, you may have noticed a letter about the U.S. Senate Committee on Finance’s hearing, “A Pathway to Improving Care for Medicare Patients with Chronic Conditions.” At a hearing on May 15, Chairman Orrin G. Hatch and Ranking Member Ron Wyden formed a full Finance Committee chronic care working group, co-chaired by Senator Johnny Isakson and Senator Mark R. Warner. I encourage you to read the letter to stakeholders that was signed by the above four members of the Senate. See www.finance.senate.gov/newsroom/chairman/release/?id=9f9f2d3e-401e-409b-a53a-22bbe3f56f2c. You can also search on “Chronic Care Working Group Letter.pdf”.

As I reflect on all that we learn at conferences such as the World Congress of Lymphology and Patient Summit, I hope that we patients find strength in our collective ability to make the change we wish to see. Just as we learn to manage our disease, we also learn that we can join forces with other advocates and activists on behalf of lymphedema, lipedema, and related diseases.

Good wishes,

Pat

Patricia Egan, MS, MBA
Chair, Board of Directors

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