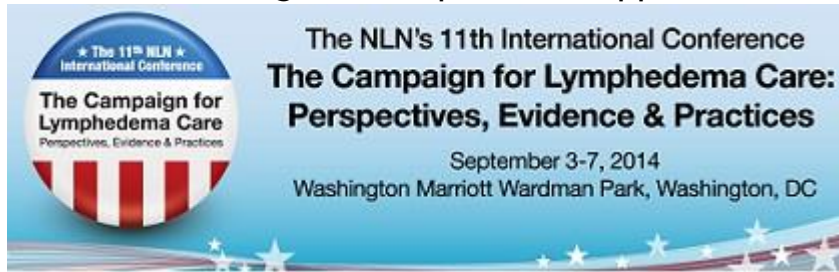


## ONLINE FIRST: Lymphedema Conference Stresses Need for Better Education, Medicare Coverage of Compression Supplies



**BY PEGGY EASTMAN**

Tuesday, September 09, 2014

WASHINGTON—After years of languishing on the back burner, lymphedema is now being recognized as an increasingly important health care issue, according to speakers here at the 11th National Lymphedema Network (NLN) International Conference.

Speakers and conference participants emphasized the need for better professional and patient education; high-quality medical treatment for all patients at risk for or affected by lymphedema; insurance coverage of compression supplies; and expansion of the number of lymphedema treatment centers and certified lymphedema therapists (CLTs).

Health professionals are now increasingly aware of the importance of early detection of lymphedema, risk reduction, and possibly prevention, said Kathleen Francis, MD, Medical Director of Lymphedema Physician Services at St. Barnabas Ambulatory Care Center in Livingston, NJ, who moderated a session on breast cancer-related lymphedema detection and risk reduction.

Marga F. Massey, MD, CLT, a surgeon, who is founder and Chief Participating Investigator of the National Institute of Lymphology in Chicago, told *OT* that she had taken time to complete a two-week course to become a certified lymphedema therapist because she believes so strongly in the need for high-quality lymphedema care: "Anybody involved with this patient population should study lymphedema," she said. "My vision is that every single nurse should undergo CLT training."

### **Lymphedema Treatment Act (H.R.3877)**

Conference participants urged Congress to pass the Lymphedema Treatment Act (H.R. 3877), which is supported by the NLN, the American Cancer Society, the Oncology Nursing Society, Susan G. Komen for the Cure, and LIVESTRONG, among others. This act would change Medicare law to allow coverage of the physician-prescribed lymphedema compression supplies many cancer patients use daily, including gradient compression garments, bandages, and devices such as reduction kits.

Currently, Medicare does not cover these mainstay treatment supplies; the lymphedema community hopes that if Medicare approves coverage of compression supplies, other insurers will follow suit. The Act was introduced in January by Rep. David G. Reichert (R-WA).

The aim is to support patients' adherence to their maintenance phase of treatment by covering compression supplies and to reduce total lymphedema health care costs by decreasing the incidence of complications, co-morbidities, and disabilities resulting from lymphedema.

NLN notes that many lymphedema patients cannot afford compression supplies, and thus suffer from recurrent infections, worsening of their condition and eventual disability. The Lymphedema Advocacy Group is leading the effort to pass the Lymphedema Treatment Act, and conference participants visited Capitol Hill to lobby for the Act's passage.

### **'Protect the Limb' Protocol**

At the conference, Massey presented results of a study on her proactive Protect the Limb protocol, which seeks to lower patients' risk of developing breast cancer-related lymphedema (BCRL). In this study at St. Charles Surgical Hospital in New Orleans of 2,966 consecutive patients, the patients underwent a protocol of education and participative decision-making about breast cancer-related lymphedema overall as well as on the sites for future at-risk interventions such as venipuncture, IV catheter placement, and blood pressure monitoring prior to the day of surgery.

The patient education was given by a CLT and took two hours. "We hypothesized that giving tools for patients to proactively participate in making decisions that may alter their risk of developing BCRL would be a major contributor to patient satisfaction with their hospital care," she said. "In our practice we've used lots of tools for patient education."

Patients were given copies of NLN position papers for home study. At a second meeting, an 89-item questionnaire was administered by the peri-operative nursing staff to determine a numerical BCRL risk score for each limb. That score was translated into a risk-associated color code for each limb; the patients and anesthesiologist then selected which limb(s) were appropriate for at-risk interventions before any additional testing or procedures were done.

For example, she said, red means "stop;" yellow means "caution" related to an at-risk extremity; and green means "go" – that is, the limb is cleared for procedures.

"All patients who went through the Protect the Limb protocol said that that the ability to participate in proactively determining how to reduce their potential risk of BCRL prior to surgery was a major contributor to their overall satisfaction in their hospital care," Massey said. She and her team concluded that "system-wide educational programs can be developed to educate patients as to risk-reduction practices for BCRL."

Asked who on the breast cancer patient's care team is responsible for patient education on lymphedema, Massey said that job falls to everyone, but it should be led by a certified lymphedema therapist: "I had to go and become a CLT so I could educate myself," she said. "Then I had to go and educate others in the hospital. It was a relatively large task to get everybody on board."

For example, she said, anesthesiologists knew little about lymphedema. She added that getting a buy-in from surgeons for a patient education protocol such as Protect the Limb is "very hard, and takes effort." Is it practical, though for surgeons to take CLT training, as she did? "Why not?" she answered. "It only takes two weeks. No one has a fuller surgical schedule than I do."

### **Prospective Surveillance Model for Rehabilitation for Women with Breast Cancer**

A second noteworthy study at the conference presented the first report of implementation of the Prospective Surveillance Model (PSM) for Rehabilitation for Women with Breast Cancer, which is aimed at early detection of, and intervention for, lymphedema.

In this feasibility study at Grady Memorial Hospital, a large inner-city facility in Atlanta, 100 subjects with Stages 0-III breast cancer received education related to lymphedema risk reduction, treatment side effects, and the importance of both early therapeutic range-of-motion exercise and ongoing exercise habits. Each patient had a patient navigator.

The lead author Jill Binkley, PT, MSc, CLT, Executive Director of TurningPoint Breast Cancer Rehabilitation in Atlanta reported that about 35 percent of women admitted to the two-year PSM study required further physical therapy intervention, including lymphedema management. Early, mild lymphedema was detected and treated in 18 percent of patients.

PSM education helped to maintain a low level of lymphedema in the majority of patients, she said, adding that the protocol “serves to empower women to self-manage and to know when to return to us for further treatment.”

### **Differences in Lymphedema Based on One or Two Mastectomies?**

Another study of 916 surveys from 229 women – conducted at Massachusetts General Hospital – who had either a unilateral or bilateral mastectomy found no difference in breast cancer-related lymphedema, based on an analysis of 355 mastectomies, between those who had one breast removed and those who had two breasts removed.

There were also no significant differences in mean arm function score and quality of life, said lead author Meyha N. Swaroop, an investigator in Massachusetts General Hospital’s Department of Radiation Oncology. Kathleen Francis, MD, commented as moderator, “Since all of us are seeing more and more bilateral mastectomies, this kind of information is very important to have.”

### **With/Without Axillary Surgery**

Finally, another study from Massachusetts General Hospital of 348 breast cancer patients over age 65 explored BCRL in those who underwent breast surgery with or without axillary surgery. This study showed that in elderly patients, staging the axilla with sentinel lymph node (SLN) biopsy compared with no axillary surgery is associated with a similar risk of breast cancer-related lymphedema, as well as similar postoperative complications and locoregional recurrence.

Therefore, said lead author Chantal M. Ferguson, the decision to proceed with SLN should be based not on age but “on how the pathologic nodal information will influence decisions regarding adjuvant treatment.”