



November 18, 2010

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National Lymphedema Network, Inc.
116 New Montgomery Street, Suite 235
San Francisco, CA 94105

Tel: (415) 908-3681
Fax: (415) 908-3813
Infoline: 800-541-3259

Email: nln@lymphnet.org
Website: www.lymphnet.org

*The NLN is a 501(c)(3)
Non-profit organization*

Editor of the Washington Post

Dear Sir/Madam,

As Executive Director of the National Lymphedema Network (NLN), I join the NLN Medical Advisory Committee in applauding you for covering the often overlooked condition of lymphedema in the Washington Post. (Nov 9) Lymphedema and lymphatic disorders continue to be largely ignored in the medical community in spite of the fact that millions of Americans, including many with cancer-related lymphedema, suffer from this chronic, incurable, and often debilitating condition.

The NLN Medical Advisory Committee wishes to respond to a comment about pain and lymphedema published in the Nov 16 letters section in which Nicole Stout, a respected lymphedema clinician and researcher, stated that "lymphedema in itself is not a painful condition, nor should it be" and "pain...is commonly a sign of a more serious medical condition".

In actuality, research indicates that many patients suffer significant pain and discomfort associated with the lymphedema itself, which often ameliorates with appropriate treatment of the swelling. However, since Ms. Stout is correct in pointing out that in certain cases pain may indicate a more serious medical condition, the NLN emphasizes that thorough medical evaluation of all symptoms associated with lymphedema, including pain, is necessary to rule out other causes of symptoms.

Since publication of Ms. Stout's letter, we have received numerous calls from patients with lymphedema expressing confusion, anger and fear occasioned by Ms. Stout's remarks. As an internationally recognized grassroots organization whose mission is to serve and advocate for people with lymphedema and the professionals who treat this disorder, the NLN wishes to help clarify the issue.

Respectfully,

Saskia R.J. Thiadens RN
Executive Director

Cc; NLN Medical Advisory Committee.