

The Lymphatic Research Foundation (LRF) National Lymphatic Disease and Lymphedema Registry

I would like to update you on my November 5 post “One-Stop Searchable lymphedema Online Database in the Works”:

Following the posting, Sheila Ridner, Assistant Professor at Vanderbilt University School of Nursing, Nashville, TN, and a member of the Board of Directors of the Lymphatic Research Foundation (LRF) contacted me to make me aware that the LRF already established a fully functional national lymphedema database.



The LRF is an internationally recognized, not-for-profit organization with the goal of promoting significant advances in research for lymphedema and other lymphatic diseases, and to find effective treatments and ultimately a cure for this condition. The LRF was founded by Wendy Chaite after her daughter was born with systemic lymphatic disease and lymphedema. Searching for medical and scientific answers and treatment she was shocked and frustrated by the lack of information and knowledge about lymphedema. Wendy knew that without aggressive research into the lymphatic system, there could be no progress in clinical care. Her response to the situation was to leave her successful career as a lawyer and to form the Lymphatic Research Foundation.

The LRF’s lymphedema database was established in 2009 in cooperation with the North Shore Informatics Group, located at the Feinstein Institute for Medical Research of the North Shore-Long Island Jewish Health System and Sanford University.

The goal of this confidential database is to acquire information about the characteristics of people affected by lymphatic diseases and lymphedema, to gain information on the natural history of lymphatic diseases and lymphedema, and to quantitate and characterize the impact of these diseases on those affected and their families. This comprehensive registry will serve as a repository of information that will enhance the future ability of health care professionals to accurately identify, categorize, treat and prevent these diseases.

The LRF invites and encourages the lymphedema patient community to participate in this highly significant development. A national patient registry paves the way for future clinical trials of experimental drugs and therapies designed to treat lymphatic diseases.

To find out more about the database, and register please go to:
<http://registry.lymphaticresearch.org/>