

Lymph Science Advocacy Program (LSAP)

A Training Program for Advocates for Research and Education about Lymphedema

The National Lymphedema Network (NLN), in response to needs identified by lymphedema (LE) patients, caregivers and advocates, has created a program to educate advocates in the basic science of Lymphedema and related disorders. Participants will be selected from submitted nominations and will represent a diversity of backgrounds and interests including primary and secondary LE from related causes. The selected candidates will be able to attend the 8th NLN Conference, *Lymphedema: Riding the Wave of Discovery*, which will be held August 27-31, 2008. The program will be limited to 5 new participants.

Program Goal

The goal of the Lymph Science Advocacy Program (LSAP) is to engage and motivate patient advocates and caregivers to action in issues of treatment and research of the lymphatic system through education and a more comprehensive understanding of the scientific and clinical research aspects of primary and secondary Lymphedema and related disorders.

Program Highlights

- Participate in 2 webinars prior to the meeting
- Individualized guidance on topic areas
- Introduction to the clinical research process
- Mentors and scientific guidance
- Opportunity to participate in discussion groups with expert lymphologists and therapists
- Individualized action plan for dissemination and use of knowledge gained through the LSAP Program

Expected Outcomes of the Program

The National Lymphedema Network expects program participants to:

- Gain a unique perspective and understanding about the basic research process
- Foster ideas and partnerships for new approaches and research
- A stronger commitment from participants in addressing the issues through advocacy in research, legislative and educational means
- Cast a broader “net” for inclusion of the NLN mission in all areas of LE research, treatment, prevention and education.

Guidelines

Participants approved for the program will be expected to:

- Register and attend the pre-conference webinars and all designated sessions throughout the conference. LSAP participants should stay through the entire conference and not plan an early departure.
- Conduct themselves during the session in a manner respectful of the program
- Approach the subject topics with interest and an inquisitive mind
- Keep the scientific/research aspects top of mind throughout the program. While many of us are more comfortable discussing outreach activities and events the LSAP participants will be dedicated to learning more about medical research and the impact on patient care.
- Prepare written reports and return all evaluation surveys and participate in follow-up discussions designed by program organizers.
- Serve as an educational liaison following the program to other lymphedema patients and interested parties, including support groups
- Participate in developing a group action plan for continuing education following the conference

Program Faculty

TBA

LSAP Participants Schedule:

Wednesday - August 27, 2008
1:00 - 5:00 PM

PRE-CONFERENCE INSTRUCTIONAL SEMINARS

[PC1] The Essentials of Wound Care for Lymphedema

[PC2] Practical Management of the Morbidly Obese Lymphedema Patient

[PC3] Responding to Non Compliance and Preventing Personal Burn Out

Thursday, August 28, 2008

6:30am–8:00am Registration Check-In/Continental Breakfast/ Exhibits/Posters
(in Exhibit Pavilion)

8:00am–8:30am Opening Ceremony
Keynote Speaker: John Bergen, MD, FACS, FRCS

8:30am–5:00pm **PLENARY SESSIONS**

THE LYMPHATIC SYSTEM AND LYMPHEDEMA

Lymphedema and its manifestations

Differential diagnosis and related morbidities

Physiology/Pathophysiology of the Lymphatic System

MANAGEMENT OF LYMPHEDEMA

Conventional, Alternative and Investigational Treatments

Medical ethics in the treatment of LE

Case studies from around the World

Diet and Nutrition

BASIC, APPLIED AND TRANSLATIONAL RESEARCH

Genetics and Lymphedema
Lymphangiogenesis and Molecular Function of the Lymphatic System
Clinical Lymphedema Research
Refereed Papers
Quality of Life and psychosocial Issues

Noon-1:30pm Lunch Break/Exhibits/Posters

Note: *As the 8th NLN Conference is a forum for presentation of the latest developments in Lymphology related to the Conference theme, we are soliciting abstracts for oral and poster presentations featuring original research, theoretical development and clinical management in Lymphology.*

6:00–8:00 pm Reception (*Exhibit Pavilion – for attendees only*)

Friday, August 29, 2008

7:00am-8:00am Registration Check-In/Continental Breakfast/Exhibits/ Posters

INSTRUCTIONAL SESSIONS – outlines for each session can be found on the NLN website

8:00am-9:45am

- [H1] Differential Diagnosis: Deciphering Edema
- [H2] Integrating Anatomy and Physiology into Lymphedema Management
- [H3] Problem Solving: Creative Solutions for New Lymphedema Therapists
- [H4] Therapeutic Approaches to Breast Cancer Related Soft Tissue Dysfunction
- [H5] Health Insurance and Insurance Updates

10:15am-12:00pm

- [H6] Pediatric and Adolescent Challenges
- [H7] Advanced Problem Solving for the Experienced Lymphedema Therapist
- [H8] Innovative Solutions for Truncal and Genital Lymphedema
- [H9] Perometry and Bioimpedence
- [H10] Traditional and Non Traditional Pharmacological Approaches

12:00pm-1:30pm

Lunch Break/Exhibits/Posters

1:30pm-3:15pm

- [H11] Establishing and Marketing a Successful Lymphedema Practice
- [H12] Palliative Care: Providing Comfort through Lymphedema Therapy
- [H13] Position Papers
- [H14] Truncal and Genital Lymphedema: Strategies for Effective Management
- [H15] Head and Neck Lymphedema

3:45pm-5:30pm

- [H16] The Venous Lymphatic Connection
- [H17] Lymphedema Emergencies: Recognizing Red Flags
- [H18] Grantsmanship - Helpful Hints for a Successful Grant
- [H19] Genetics 101

NLN

Saturday, August 30, 2008

7:00am–8:30am Roundtable Sessions I
Sign-up on-site Thursday and Friday

7:00am–8:30am Registration Check-In/ Continental Breakfast *(in Exhibit Pavilion)*

7:30am–11:00am Exhibits/Posters

8:30am–5:00pm PLENARY & CONCURRENT SESSIONS
See Thursday for topics

Noon–2:00pm Luncheon – Keynote Speaker: Christine Moffatt, PhD, MA, RGN, DN

Sunday, August 31, 2008

7:30am–9:00am Roundtable Sessions II
Sign-up on-site Thursday and Friday

9:00am–11:00am LATE BREAKING RESEARCH

11:00am–11:15am Conference Wrap-Up

APPLICATION PROCESS

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During the 8th NLN Conference, taking place August 27 – 31, 2008 the LSAP program, established by the National Lymphedema Network will offer patient advocates the chance to become educated in the science and issues of Lymphedema and related disorders.

The two (2) webinars will take place at the end of July and early August.

The onsite program will be offered at the National Lymphedema Network's 8th International Conference in San Diego, CA, August 27 – 31, 2008. The program will be limited to 5 NEW participants. Participants will be selected from submitted nominations and will represent a diversity of backgrounds and interests (primary, secondary from breast, gynecological, melanoma, unrelated to cancer).

Nominations:

Applicant may self nominate or be sponsored by an organization. Forms for application are enclosed.

Eligibility:

Patients affected with LE, caregivers or those whose lives have been affected by lymphedema may apply. Applicants must show a curiosity and interest in learning scientific principles and research methods, including the clinical trial process, and be able to function as an observer in scientific and instructional sessions.

Requirements:

- Complete application
- Narrative description of your interest in participating in the project (no more than two pages)
- Resume or curriculum vitae (CV) of applicant (please include volunteer responsibilities)
- Two letters of support

Registration Fees, Housing and Travel:

Selected applicants will be responsible for all conference costs, registration fees, and travel. These costs may be underwritten by the supporting organization or the applicant.

Schedule:

- The **webinar panels** will take place between the last week of July and the first week of August. Specific dates and times will be communicated to candidates upon acceptance.
- The **onsite program** will begin on August 27th and conclude on August 31st.



LSAP APPLICATION FORM COVER SHEET

The National Lymphedema Network (NLN) is accepting nominations for participation in the Lymph Science Advocacy Program (LSAP). The objective of this program is to educate and motivate lymphedema patients and caregivers to action by gaining a comprehensive understanding of the science and issues surrounding lymphedema.

Each application should include this cover sheet and requested attachments.

Applicant's Name: _____

Address: _____

City: _____ **State:** _____ **Zip:** _____

Phone: _____ **Fax:** _____

Email: _____

Nomination:

Applicant is: Self-nominated Nominated by sponsoring organization:

How you plan to share the information/knowledge:

Do you have a constituency group that would serve as a conduit for sharing the information/knowledge that you gain through this program?

Yes If yes, please describe the group.

No If no, please explain how you intend to share the information and apply the knowledge gained through this program.

You may use additional sheets, if necessary.