

NATIONAL LYMPHEDEMA NETWORK

Saskia RJ Thiadens

In 1988 the National Lymphedema Network® (NLN®) was established by Saskia RJ Thiadens, in response to a growing need for awareness, education and, most importantly, an effective treatment for lymphoedema. Recognised both nationally and internationally, the NLN is a California-based 501(c)3 non-profit organisation dedicated to diminishing the suffering of lymphoedema patients through education, service and research. The NLN makes available information on all aspects of lymphoedema through its toll-free line, direct dial referral service, educational website, quarterly newsletter, and biennial conferences.

Key words

Lymphoedema clinic
Awareness
Education
Research
Reimbursement

My first encounter with the relatively unknown syndrome, 'lymphoedema', was in 1985. I ran Aurora Manor, a post-operative care facility in San Francisco, where I saw a patient with an extremely enlarged swollen arm. She had undergone breast reconstruction after a mastectomy and it appeared that she had had an allergic reaction from the intravenous infusion.

I immediately called her surgeon and expressed my concern. He laughed and told me she had had the swelling in her arm for nine years, and there was nothing that could be done to improve it. I was both puzzled and inquisitive as to the underlying cause/s and possible treatment. I turned to local colleagues; they each told me that it was lymphoedema as a result of her breast cancer surgery, and no effective treatment was available.

Shortly thereafter, I opened the first lymphoedema clinic in the United States

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(Aurora Lymphedema Clinic, 1987), and quickly became aware of the enormity of lymphoedema and its unknowns. The phone did not stop; both young and old with swollen arms/legs were calling the clinic, hoping that I could help them.

I soon realised that this was much bigger than I had anticipated, prompting me to found the National Lymphedema Network® (NLN®) which is now comprised of healthcare providers, researchers, lymphoedema patients and patient advocates — all dedicated to making authoritative information on lymphoedema available to the medical profession, patients with lymphoedema and the general public. The NLN subsequently adopted a 'mission statement' to establish its goals:

The Mission of the NLN 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.

Additionally, the NLN is dedicated to:

- ▶ Promoting lymphology as a medical specialty
- ▶ Adopting standards acceptable to the United States medical profession, for the training and certification of lymphoedema therapists
- ▶ Securing adequate insurance coverage of medically necessary, safe and effective treatment
- ▶ Expanding the number and geographical distribution of

lymphoedema treatment facilities and certified lymphoedema therapists

- ▶ Promoting research in the causes, risk reduction and treatment of lymphoedema.

It was important for me to expand my knowledge of this disabling condition as quickly as possible in order to give relief to the ever-increasing numbers of patients presenting themselves daily at the clinic. I soon found that there were no doctors and no other healthcare professionals able to diagnose, treat, or refer patients with lymphoedema.

My journey began with only a few patients, but soon I found myself advocating for the thousands of people suffering with this ignored disease. Now 20 years later, the NLN has joined forces with the oncological community as well as other disciplines. Lymphoedema is now identified as a legitimate disease in the United States. The most current standard treatment, complete decongestive therapy (CDT), is in place at university-based clinics, hospitals, rehabilitation centres and free-standing facilities; thousands of clinicians have become certified lymphoedema therapists; physicians have included the lymphatic system in their existing practice; research is in progress in academic institutions; and patients are actively advocating for their rights and convincing their state and federal representatives to get laws in place to support proper treatment and reimbursement.

Our ultimate goal is to ensure that all patients with lymphatic disorders receive the care that they deserve.

Chronological history of the National Lymphedema Network (NLN)

In January 1989 the NLN established membership in this non-profit organisation to better disseminate information about lymphoedema. Numerous massage therapists, a physical therapist, a physician (Dr Joseph Feldman), and many of the Aurora Lymphedema Clinic patients joined and the NLN Newsletter was published. This was an informative periodical which was subsequently mailed to cancer centres across the US, along with distribution to the delegates at the various breast cancer conferences I attended.

A board of directors was formed — an enthusiastic group of business people consisting of an accountant, a lawyer, surgical and medical oncologist, and an Aurora patient.

Nevertheless, with the lack of interest and continuing resistance in the US to this mostly unknown illness, I chose to look abroad for much-needed knowledge and support. I learned about the International Society of Lymphology (ISL), and their XVII Congress which was to be held in Tokyo that year. I was able to attend this eye-opening conference and found that there was great interest in the basic science of the lymphatic system which, in turn, offered hope for the future of patients with lymphatic disorders.

In 1990–1991, I formed the first NLN lymphoedema support group in San Francisco and was overwhelmed by the number of patients and family members hungry for information and help. We began holding active monthly group meetings with an array of renowned speakers.

At the same time, numerous professionals from around the country contacted me, expressing an interest in joining the NLN as a support/treatment facility. Eighteen lymphoedema treatment support programmes were established nationwide and subsequently listed in a 'Resource guide' in our newsletter.

Prevention, an international consumer magazine, published its first article on lymphoedema, calling it the 'ballooning limb' syndrome. This was our first national/international outreach and we were immediately bombarded with phone calls from people around the world requesting further information about lymphoedema and the NLN.

In 1993 I represented the committee at the ISL Conference in Washington, DC, bringing 40 pioneering patients from around the country to this scientific congress, an action unheard of at that time. These patients provided a reality check of actual complex cases which they presented during a specially organised patient clinic. Such clinics have now become standard during scientific lymphology conferences.

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The first NLN International Conference took place in San Francisco in 1994, drawing an amazing 300+ healthcare professionals and patients from around the world. The NLN began global networking, acting as a central information centre for the US lymphoedema community.

On 6 March, 1994, the NLN founded Lymphoedema D-day, a special day set aside each year to honour inspirational patients: those who have contributed to the community or who have shown great courage in their struggle with disease. Since our first D-day celebration, hundreds of patients and healthcare professionals throughout the country have been honoured. Such results receive both local and national media exposure, helping to make the world aware that lymphoedema is no longer a rare condition.

NLN educational workshops were set up in 1995 on the West Coast and we were participating and exhibiting at national oncology conferences,

reaching out to oncological disciplines throughout the country; and joining breast cancer rallies with excellent networking results.

At this time, the lymphoedema professional community began to break into camps due to lack of standards/guidelines for 'appropriate' treatment and training of professionals. This chaotic climate continued until 1998 and the NLN was in the midst of it until the need for unity among the various training courses was realised. Eventually in 1998, all instructors of schools and other key players met and, together, founded the Lymphology Association of North America (LANA). This non-profit organisation promotes training standards for lymphoedema therapists, administering North American certification examinations to test knowledge considered fundamental in the treatment of lymphoedema. Today, 869 therapists are certified by LANA promoting awareness of lymphoedema and attracting more healthcare professionals to the field of lymphology.

The second biennial NLN International Conference on lymphoedema was held in 1996 in San Francisco. Scepticism, however, continued in the medical community and so we increased efforts to educate patients, especially at grass-roots level. Patients began to become aware of effective treatment and many of them, angry and frustrated, became the first American lymphoedema activists. Local efforts to effect change in the medical community started in countrywide neighbourhoods with the NLN as the central clearinghouse.

The NLN also established an online website, www.lymphnet.org, and received overwhelming response from patients and professionals internationally.

In 1997 the NLN participated in breast cancer legislation circulating petitions nationwide. With the efforts of Dr Ernie Bodai, a local breast surgical oncologist representing the NLN, a landmark rider was added to both a California State and a Federal

bill, each of which provided insurance coverage for treatment of patients who developed lymphoedema post-breast cancer surgery.

A new and expanded board of directors was formed along with a medical advisory committee (MAC) and an international advisory committee. The NLN became involved in the planning of major projects funded through the submission of grant applications to various sources.

The Lymphedema Alert bracelets, designed by Karin Douglas, a breast cancer and lymphoedema activist, were produced as a fundraiser and educational tool for the NLN. Presently, the NLN sells over 3,000 bracelets per month to patients with and at risk of lymphoedema (Figure 1).

We had our 10-year anniversary in 1998 and the third International Conference, 'Lymphedema: Uncovering The Hidden Epidemic', was held in San Francisco, CA, with over 500 physicians, nurses, physical and occupational therapists, massage therapists and patients attending.

In 1999 the NLN Organizational Development Plan was implemented. Additional plans that year included technological upgrades to improve information/database management, outreach and self-sufficiency. The NLN was accepted as a recipient of donations from the Local Independent Charities and United Way Fundraising Campaigns (1999–2000), and continues to receive matching contributions each month.

The 4th International Conference was held in Orlando, Florida in 2000 with over 650+ delegates, including 200 patients from around the country, some of whom presented their own case history during the patient clinic.

A nationwide NLN Insurance Coverage Task Force was organised, consisting of patient activists and healthcare professionals working together on a national level, as well as independently in their local communities, to promote and secure

insurance coverage for lymphoedema treatment. A formal request was submitted to Medicare for a national coverage decision on CDT for the treatment of lymphoedema, under the rehabilitation benefit.

The NLN launched a nationwide campaign to promote submission and passage of statewide resolutions designating 6 March as Lymphedema Awareness D-Day, with the goal of a national resolution instituted by 6 March, 2001. Virginia was the first state to adopt the resolution; in the years since, 32 states have followed.

From 2002 to 2006 the NLN International Conference continued to be held biennially in Chicago, Illinois, Reno, Nevada, Nashville, and Tennessee, respectively. Clearly, the field of lymphology is growing, and more basic, clinical and genetic research continue at academic institutions worldwide. In 2005, the landmark Patient Summit was organised; over 200 patients from nearly every state attended.

The 8th biennial NLN International Conference is being held 27–31 August, 2008 in San Diego, California.

An overview of the National Lymphedema Network NLN Lymphlink

The official NLN newsletter is now in its 20th year of publication. The journal has 36 pages and is distributed to members, i.e. patients, professionals, support groups, universities, doctors' offices, libraries and others. Each issue covers a specific topic related to lymphoedema and includes case studies, question corner; research perspectives, action corner; book review; legislative corner; in addition to a resource guide with a listing of training courses, support groups, affiliated clinics, therapists and suppliers.

Board and committees

The NLN board of directors meets four times each year and oversees the fiscal and organisational aspect of this non-profit organisation.

The medical advisory committee (MAC) consists of four physicians,

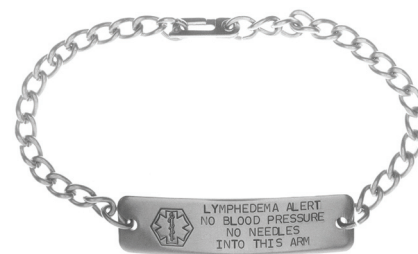


Figure 1. Lymphedema Alert bracelet.

four nurses, two physical therapists and instructors of training courses. The MAC oversees all medical-related issues, writes policies including the NLN Position Papers, and is well-respected in the medical community nationwide. NLN Position Papers are used in breast centres, hospitals, doctors' offices, lymphoedema clinics and support groups. MAC members are often called upon to lecture at various local, state and national meetings. MAC members also actively participate on the scientific NLN conference committees.

The research committee consists of two PTs, three MDs, one RN, one PhD, and two RN/PhDs — all with a strong interest and extensive experience in clinical research. Some have received National Institute of Health (NIH) grants through their academic institutions and actively do clinical research related to lymphoedema. In 2001, the committee designed an online patient survey, focusing on questions regarding causes, education, infections, incidence, and quality of life issues. The subsequent data has been presented at both national and international conferences. At the present time, the committee is reviewing the possibility of organising a two-day workshop for interested clinicians, 'How to write a fundable grant'. The research committee also screens funded lymphoedema studies to be posted on the NLN website.

Legislation

The legislation and insurance committee is headed by a strong lymphoedema legislative patient advocate, Robert 'Bob' Weiss, who has been active in improving state and federal legislation relating to lymphoedema. Faced in the political arena with ongoing insurance and legislation struggles in the US, our

legislative activists/advocates, working with the American Cancer Society lymphoedema work group, succeeded in enacting a lymphoedema treatment law in Virginia in 2004, achieving favourable action on lymphoedema insurance issues. They are presently working to establish a lymphoedema and lymphatic disease research grants programme and a comprehensive lymphoedema treatment and patient protection law in New York state. We are supporting activist groups to enact lymphoedema legislation, and have been seeking Congressional sponsors for a comprehensive lymphoedema diagnosis and treatment cost-saving bill for Medicare. Weiss and the committee have helped dozens of individual patients to obtain insurance reimbursement for treatment and garments.

Training programmes

The Lymph Science Advocacy Program (LSAP) is a training programme for advocates for research and education about lymphoedema. The goal of 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 lymphoedema and related disorders. First launched at the 2002 NLN Conference, five lymphoedema patient advocates actively participated in the scientific meeting. To qualify, patients must submit an application and identify their active involvement in advocacy and scientific interest. Presently, there are 16 LSAP graduates; patients are now applying for the 2008 NLN Conference.

Parents Lymphedema Action Network (PLAN) was developed as an information source for parents of children with lymphoedema, specifically to answer questions from desperate young parents who are unable to get answers from their paediatricians. Additionally, PLAN was set up as a support source, using the newly created 'online message board'

(NLN website) to share concerns and communicate with other young mothers and fathers who need help facing this frightening disease. PLAN's primary resolve is to improve the life of newborns and children with and at risk of lymphoedema.

Grants and financial support

As a tax-exempt organisation, the NLN relies on donations and educational grants from members, industry and friends of the NLN, in addition to conference and organisational grants from the Center of Disease Control (CDC) and the NIH, Susan G Komen Breast Cancer Foundation and the American Cancer Society. Each year, the NLN provides members with an 'End-of-the-Year' letter, describing the accomplishments during the year and goals for the year ahead. In return, members make substantial contributions to support the NLN — allowing us to continue our many projects.

The Garment Fund is a new fund established in the name of Marilyn Westbrook whose family recently made a large contribution to the NLN. It was Mrs Westbrook's wish that no other patient would have to endure what she experienced six months prior to her death in December 2007. The Marilyn Westbrook Garment Fund will enable patients who do not have insurance or the financial means to purchase much-needed lymphoedema compression garments and alternative products.

Recently, the NLN partnered with the National Accreditation Program for Breast Centers (NAPBC), a new organisation which provides standards to hundreds of breast centres in the US. The NLN offers guidance with lymphoedema awareness and education, including NLN Position Papers, and allows many professionals to become informed about pre- and post-operative guidelines, also collecting required data from hundreds of breast centres that have applied for the accreditation programme.

Staff and volunteers

The NLN has five full-time staff:

Key points

- ▶▶ The Mission of the NLN 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.
- ▶▶ Lymphoedema is now identified as a legitimate disease in the United States.
- ▶▶ In 2005, the landmark Patient Summit was organised; over 200 patients from nearly every state attended.
- ▶▶ Our primary goal in the next decade is to create awareness and interest among all disciplines and make the lymphatic system part of all medical practices.

executive director, assistant director, database/website manager, outreach coordinator and bookkeeper. The NLN also has several volunteers/patients who help with mailings, data entry and answering phones. The website receives an average of 360,000+ hits on the internet per month, plus hundreds of emails and phone calls asking medical and organisational questions. Two hours are set aside each day to respond to the patients' medical questions.

We have come so very far this past 20 years. Our greatest accomplishment being that many lymphoedema patients are now receiving standard treatment and much-needed education.

Our primary goal in the next decade is to create awareness and interest among all disciplines and make the lymphatic system part of all medical practices. We look forward to the continued growth of the NLN to achieve the ultimate common purpose of our worldwide relationships, a universal treatment and cure. 