

A HISTORY OF THE DUTCH LYMPHOEDEMA NETWORK

Robert Damstra

The Lymphedema Group Drachten was founded in 1995 in the Nij Smellinghe Hospital in Drachten, the Netherlands, to diagnose and treat patients. The Dutch Lymphology Foundation (Stichting Lymfologie Centrum Nederland, SLCN) was founded in 1998 to disseminate knowledge and experience to those working in this field and started an internet platform called The Lymphedema Network. In 2006, as there was a need for an independent patient organisation in the Netherlands, the SLCN, together with many other organisations with an interest in lymphoedema, founded the Dutch Lymphedema Network (DLN, NLNet).

Key Words

Multidisciplinary working group
Lymphoedema
Lymphoedema clinic
Guidelines

The Lymphedema Group Drachten was founded in 1995 in the Nij Smellinghe Hospital, Drachten, the Netherlands, because of the need for a better diagnostic and therapeutical perspective for patients with primary and secondary lymphoedema. The group included healthcare professionals from several disciplines, namely; dermatologists, surgeons, physiotherapists, skin therapists, nurse practitioners, compression specialists, dieticians as well as consultants in plastic surgery, gynaecology and urology. Its purpose was to diagnose and treat patients with lymphoedema in both an outpatient clinic and a lymphoedema clinic within the hospital, which worked closely with specialists in other fields.

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For the next few years the group developed from being a regional organisation into a centre of expertise for diagnostic and therapeutical interventions, cooperating with other professionals throughout the country.

The aim of the working group was to develop a guideline based on literature reviews, evidence and the expert base that covered definitions, diagnostics, indications for therapy, information for patients with lymphoedema and treatment options.

Two founding members of the group, dermatologist Robert Damstra and vascular surgeon Harry Voesten, realised that there was a need for more information about lymphoedema, so they formed the Dutch Lymphology Foundation (Stichting Lymfologie Centrum Nederland, SLCN) in 1998. The purpose of the foundation is: 'To collect and disseminate knowledge and experience to those who are involved with lymphological disorders and lymphoedema in particular; including patients (organisations) and healthcare workers' (see online at: www.slcn.nl).

Members active in the foundation carry out many activities, such as organising national courses and workshops on lymphoedema for healthcare professionals, including doctors and paramedics. It is a non-profit making institution which is actively involved in commissioning and carrying out research. Some studies have been undertaken in close cooperation with international working groups, such as the European Wound Management Association (EWMA), International Compression Club (ICC) and the Lymphoedema Framework, as well as professionals from other countries, such as: Professor Dr P Steijlen, Dermatologist, University Hospital Maastricht, The Netherlands; Professor H Partsch, Dermatologist, University of Vienna, Austria; Dr H Brorson, Plastic Surgeon, University Hospital Malmo, Sweden, and Professor C Moffatt, Professor of Nursing, Centre for Research and Implementation of Clinical Practice (CRICP), Thames Valley University, London, among others.

The Dutch Institute for Healthcare Improvement, CBO (www.cbo.nl) set up a taskforce on lymphoedema in 1999 to develop a multidisciplinary guideline for the Netherlands based on scientific- and evidence-based criteria. The working

group was composed of those involved with lymphoedema from medical, paramedical, and patient organisations.

The aim of the working group was to develop a guideline based on literature reviews, evidence and the expert base to cover definitions, diagnostics, indications for therapy, information for patients with lymphoedema and treatment options. In 2003 the final guideline was published and handed over to healthcare professionals. It includes information on:

- ▶ Early diagnostics and effective measurement, covering:
 - ▶ Aspects that should be referred to during the specific anamnesis
 - ▶ Aspects that should be evaluated during the specific examination
 - ▶ Supplementary diagnostics to determine the cause of the swelling indicated in specific situations
- ▶ Volume measurement according to Herpertz
- ▶ Therapy
- ▶ Follow-up.

To download a summary of the *National Guidelines for Lymphoedema in the Netherlands*, go online to: www.slcn.nl/s/download43a8e80be10d03f4d6c5a4027d7e7ee.pdf.

Dutch Lymphedema Network (NLNet)

Alongside the guideline, in 2000, the Dutch Lymphedema Network (DLN, NLNet) website was created by the Dutch Lymphology Foundation. This website was designed to provide more information about lymphoedema, the conditions, treatments, guidelines and so on. The site soon became recognised and has been widely accessed, receiving more than 3.5 million hits by 2007.

The website was redesigned twice and in 2004 it was certified with the HONcode — an accreditation that aims to improve the quality of medical and health information online — by the Health on the Net Foundation in Switzerland (for more information go online to: www.hon.ch).

At that time there was a need to transform the website activities to create an independent, professional nationwide patient organisation on lymphoedema which did not currently exist. Therefore, the Dutch Lymphology Foundation, the Breast Cancer Organisation, the National Organisation for Lymphological Physiotherapists, the Dutch Skin Therapists Organisation, individual patients and company representatives began to create a new platform for patients with lymphoedema and lipoedema.

This resulted in a new, widely supported organisation which adopted the name from the initial website and continued the internet platform for these groups. The new NLNet subsequently launched a biannual journal, *Lymfologica*, and organised a patient symposium. The first one on 11 November 2006 was a great success. Currently, the NLNet has 1000 members and is supported by many industries (go online to: www.lymfoedeem.nl/nlnet/view/9).

The NLNet is continuing to develop and throughout 2007 is organising local support groups, where patients can meet to exchange experiences, and healthcare professionals will be available to offer advice and support.

The NLNet is continuing to develop and throughout 2007 is organising local support groups, where patients can meet to exchange experiences, and healthcare professionals will be available to offer advice and support to those suffering from lymphoedema and lipoedema.

The internet infra-structure from NLNet will be expanded to facilitate these support groups. The website has special features for members, including an internet forum, contact details of healthcare professionals, many frequently asked questions

Key Points

- ▶ The Lymphedema Group Drachten was founded in 1995 to diagnose and treat patients.
- ▶ The Dutch Lymphology Foundation was founded in 1998 because of the need for more information about lymphoedema.
- ▶ In 2003 the *National Guidelines for Lymphoedema in the Netherlands* was published.
- ▶ The Dutch Lymphedema Network (NLNet) website was created by the Dutch Lymphology Foundation to provide more information about lymphoedema, conditions, guidelines, treatments for patients with lymphoedema and lipoedema.
- ▶ In 2006, many organisations with an interest in lymphoedema got together to transform the website activities and create an independent, professional, nationwide patient organisation on lymphoedema.

(FAQs), a free journal and discounts for the symposium. In the future, the NLNet plans to add to these activities.

With this structure, the SLCN can proliferate more as a medical centre to help patients and cooperate with other study groups. The national organisation NLNet is independent, and now the SLCN is finding that it is able to combine its knowledge with others to create an invaluable educational resource, which gives the opportunity for healthcare professionals to share their experiences and expertise to help the patients who suffer from lymphoedema and lipoedema. JL