

SOCIETY UPDATE



The Lymphoedema Association of Australia (LAA) was founded by John and Judy Casley-Smith in 1982 to encourage research into lymphoedema and to spread information among doctors, therapists and patients. Its website contains an excellent summary of information about lymphoedema, its causes and treatment, including views on bandaging and garments, as well as essential reference material. The website has been progressively updated in 2007 and contains useful suggestions to patients about the range of treatment and management options. It is strongly recommended that patients discuss these with their doctor prior to undertaking any of them. In the first quarter of 2008 the site featured a new section on recent research into lymphoedema, its symptoms and treatments, which was being conducted at Flinders University and Medical Centre. It will, however, continue to provide information which has an international perspective to it. The LAA website can be accessed at: www.lymphoedema.org.au.



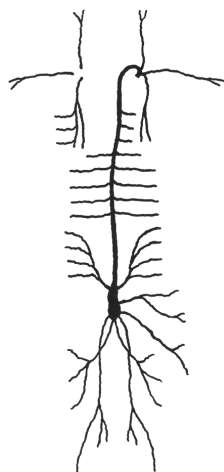
The Australasian Lymphology Association (ALA) is the peak national lymphology body for health professionals in Australia and New Zealand, which strives to improve the management of those with, and at risk of developing, lymphoedema. The association endeavours to enhance communication between health professionals, educators, relevant authorities and government in regard to oedema and lymphoedema. It advocates for equitable access to lymphoedema treatment in Australia and New Zealand. Our biennial conference is planned for 27–29 May 2010 in Melbourne, Australia. The theme of the conference is 'Lymphoedema — Reflections of the Past, Inspiration for the Future'. The ALA welcomes international colleagues to its 2010 Conference. Detailed information is available on the ALA website: www.lymphology.asn.au. At the recent 1st International Lymphoedema Framework (ILF) Conference, ALA President Kerryn Shanley and Professor Neil Piller were invited to join the International Advisory Board of the ILF and the ALA is exploring opportunities for an ILF project in Australia. The ALA believes that facilitating Australian involvement in this project will provide our best opportunity to encourage broad change in our health system, funding models and resourcing of lymphoedema services and programmes across Australasia. The ALA is continuing to work towards a graduate certificate in lymphoedema management and the development of a national lymphoedema practitioner register.



The Lymphology Association of North America (LANA) is a non-profit corporation composed of healthcare professionals, including physicians, nurses, massage therapists, physical therapists and occupational therapists, experienced in the fields of lymphology and lymphoedema. These professionals have acknowledged the need for a North American certification examination for lymphoedema therapists, to test knowledge considered fundamental in the treatment of lymphoedema. To date, we have certified over 1,000 therapists and have recertified over 300 therapists. If you wish to contact LANA for additional information, please feel free to email LANA at: lane@clt-lana.org or contact LANA by phone at: 773-756-8971. Our mailing address is LANA, P.O. Box 466, Wilmette, IL, 60091 USA.



The Israel Lymphedema Association (www.ial.org.il) held its fourth annual conference on Sunday, 3 May 2009 at the Faculty of Agriculture, Hebrew University, with the participation of approximately 160 lymphoedema patients and their families, physical therapists, other medical personnel, physical therapy students and representatives of the Israel Cancer Association. Ongoing activity of the Association includes support groups in various parts of the country, including initiation of a new group in the central area in March 2009. Programmes of the support groups, led by lymphoedema patients and physical therapists certified to treat lymphoedema, include guest speakers, interaction between patients, their families and others and presentations by group members or invited guests. One of the Association's projects for the coming year includes contact with various health funds in Israel's national health system to discuss and promote benefits and support available to lymphoedema patients. A representative of the Association participates in meetings with representatives of the funds in order to advance our interests and to ensure that the rights accruing to patients are received in practice.

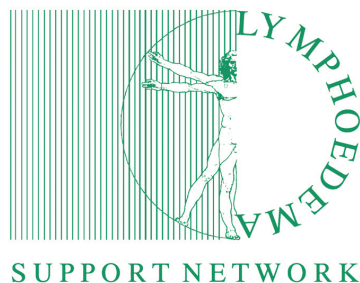


In September 2009, the Scandinavian Forum of Lymphedema held a conference in Oslo to celebrate 20 years of work. During this time, over 500 physiotherapists in Norway, Denmark, Sweden and the Faro Islands have been taught decongestive lymphatic treatment (CPD). Before that, from 1984–1989, only 10 physiotherapists had their education in CPD at the 'Földi-school' in Germany. Since 1985, together with the lymphoedema patient association (NLF), the forum has been giving information to doctors and therapists. Physiotherapists in Norway have their own professional group within the Norwegian Physiotherapist Association (NFF) and, in 1997, CPD was included in the Norwegian procedure for cancer treatment. In 2000, the NFF initiated oncological and lymphological physiotherapy as a specialty. To qualify in this field requires 800 hours of physiotherapist-specific in-service courses in this area, as well as courses in oncology and research. To maintain this specialty, documentation must be provided after seven years that you are still active within the profession and that you have participated in a peer mentoring group. In 2002, the Forum arranged the first congress in lymphology in Scandinavia for physiotherapists. It took place in Oslo. Subsequently, Sweden as well as Denmark have had their congresses and we are looking forward to the next congress to be arranged in Finland, 2010.

For more information: www.lymfologi.no.



The highlight of the past six months has been BLS Lymphoedema Awareness Week, 20–26 April. Over 35 events including coffee mornings, poster displays and information sessions were run by BLS members throughout the UK. Advice on lymphoedema and its diagnosis was sent to every single GP practice in the country and over 5000 patient guidance leaflets were handed out. Extensive press coverage has been established and maintained with a major article in the *Daily Mail* only last month. The benefit to BLS from raised awareness has been considerable. More pharmaceutical companies are now recognising the relevance of their products to lymphoedema and its related conditions. As a result, BLS has seen a 50% increase in the number of its corporate sponsors. BLS played a major role in the International Lymphoedema Conference at Ascot (21–23 April) which was organised and hosted by Wounds UK. This was a highly successful event and BLS look forward to further collaboration with Wounds UK in the future, while maintaining the constructive partnerships that have been built with the International Lymphoedema Framework (ILF) and the Lymphoedema Support Network (LSN). October will see the BLS Annual Conference being held in Sheffield. 2009 will see more speakers, more delegates and a greater number of exhibitors than ever before. It is hoped that the momentum generated by Awareness Week will continue to grow and be given a further boost by the Sheffield Conference.



The LSN takes the lead role in educating and supporting patients and is the largest information resource for lymphoedema in the UK, providing two self-help DVDs and 22 gold standard fact sheets that are widely distributed to patients, hospitals and lymphoedema clinics throughout the country. The LSN is also committed to raising awareness of lymphoedema as a major health condition to patients, health authorities, healthcare professionals and politicians and actively campaigns for improved national standards of care. The LSN is delighted to announce the launch of its new 'self-management for lymphoedema' DVDs, narrated by the Charity's Patron, Zoe Wanamaker. The DVDs feature information on lymphoedema, exercise, the application and care of compression garments and skin care together with an easy to follow simple lymphatic drainage self-massage technique. There is also a section where a variety of people living with lymphoedema talk about their personal experiences of the condition, these are practical, powerful and often moving accounts of the reality of lymphoedema.

For more information visit: www.lymphoedema.org/lsn

Telephone: 0207 351 09900.



The Leg Club model, a pioneering social approach to the treatment of conditions of the lower limb and leg ulcers, is being used as a source of reference by the Department of Health in its Quality, Innovation, Productivity and Prevention programme (QIPP). QIPP is key to building on the progress made in implementing the commitments set out in Lord Darzi's White Paper, 'High Quality Care for All'. The DoH references the benefits of the Leg Club model which include: reduced costs as a result of fewer home visits; care delivered in a non-medical setting without the need for appointments; patients encouraged and supported by peers; care coordinated with other services.

There is generally strength in numbers and charities would do well to take this to heart, especially when the hard financial times hit. The Network for Patients met for its inaugural meeting in May in London led by the Patients Association (www.patients-association.com). The Leg Club Foundation, alongside 24 other charities, showed their determination to work together to generate the most influential voice possible wherever and whenever the decisions that affect patients are being made. There was enthusiastic agreement to meet again and work on behalf of their members, while retaining each organisation's autonomy, and to do so in the most efficient and effective way.

In June the Leg Club Foundation was delighted to receive recognition as a finalist at the HealthInvestor Awards 2009, for its work relating to public health. Also in June, the Foundation Trustees were delighted to receive a highly commended award at the Wounds UK annual awards ceremony in the 'Innovation in Patient Care' category for the work that the charity has undertaken relating to patient-centred care.



MLDUK was formed in 1995 to educate healthcare professionals and the general public about the benefits of manual lymph drainage (MLD) and its applications for lymphoedema and other conditions. MLDUK maintains a high standard for the practise of MLD in the UK. It has also been our role to give the public confidence in choosing an MLD therapist, as those on our register must show proof of having completed training in one of the four main schools (Casley-Smith, Földi, Leduc and Vodder), and also that they are both insured and up to date in their practice. MLDUK publishes a list of recognised courses for therapist training and also a register of qualified practitioners. It has a helpline for anyone seeking information about MLD and maintains a website with both practical information and training courses. Last year the charity MLDUK Lymfund was launched. Lymfund offers funding for a limited number of MLD/CDT treatment sessions for those patients in dire need who are being seen by a member of MLDUK. The 2010 Annual Conference will be held in High Wycombe on the 8th and 9th May 2010 — please contact the administrator for more details. Contact MLDUK on 0844 800 1988 or visit the website: www.mlduk.org.uk.



The Global Alliance to Eliminate Lymphatic Filariasis (GAELF) was formed in 2000 with the sole purpose of supporting the Global Programme to Eliminate Lymphatic Filariasis (GPELF), which is based in the Department for Neglected Tropical Diseases at the World Health Organization (WHO). GPELF currently reaches 48 of the 81 endemic countries and is expanding each year. GAELF provides fundraising, advocacy, communications and technical assistance in support of the GPELF's two goals:

1. The elimination of LF as a public health problem by 2020
 2. The alleviation of physical, social and economic hardship in individuals who have LF-induced disability.
- Further details of GAELF can be found at www.filaria.org, or by contacting the Secretariat based at the Liverpool School of Tropical Medicine (email: gaelf@liv.ac.uk).



The Austrian LymphLiga (ÖLL) is a non-profit organisation founded in 1994 to provide information and support to lymphoedema patients and healthcare professionals. The ÖLL also endeavours to raise awareness of lymphoedema as an underestimated disease to health authorities, politicians and the general public. The ÖLL publishes a newsletter twice a year and holds regular local seminars for patients. A biennial national congress for health professionals is also organised by the ÖLL to promote the interdisciplinary collaboration and to provide the latest update on lymphology research. For more information please go online to: www.lymphoedem.at.