

# SOCIETY UPDATE



PROMOTING PROFESSIONAL LYMPHOEDEMA SERVICES

20th April sees the start of the British Lymphology Society's major attempt to increase awareness and understanding of lymphoedema among healthcare professionals, patients and the public at large. BLS Lymphoedema Awareness Week runs from 20–26th April, 2009 and there will be around 20 events such as coffee mornings, poster displays and patient advisory sessions being mounted across BLS regions. Postcards outlining the five key things you need to know about lymphoedema (the '5 Guide') will be sent to GP practices, together with a penholder for GPs to have on their desks. Lymphoedema healthcare practitioners will have a patient version of the '5 Guide'. There will be promotional materials available at these events, including: cotton carrier bags, posters, pens and trolley tokens. There will be a dedicated website: [www.blsawarenessweek.co.uk](http://www.blsawarenessweek.co.uk) giving more in-depth clinical information and advice.

The highlight of the week will be the International Conference at Ascot (21–23 April). BLS will be hosting an evening reception on the first day at which we will launch the '5 Guides'; announce a joint competition for industry with the International Lymphoedema Framework (ILF); and promote our Annual Conference in Sheffield. Nick Clegg MP, Leader of the Liberal Democrats has endorsed the BLS campaign: *The BLS is playing a vital role in promoting awareness of lymphoedema both to the public and within health care. This is of crucial importance for the many people suffering with lymphoedema in the UK. I wish every success for the forthcoming campaign, and that this in turn will lead to better diagnosis, more effective treatment, and more support for those living with lymphoedema.*



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. Throughout 2009, the site will contain a progressive release of details relating to the 22nd International Congress of Lymphology which will be held in Australia in Sydney. The LAA website can be accessed at: [www.lymphoedema.org.au](http://www.lymphoedema.org.au). Preliminary details of the 22nd International Society of Lymphology (ISL) congress can be got from the site or from: [www.lymphology2009.com](http://www.lymphology2009.com).



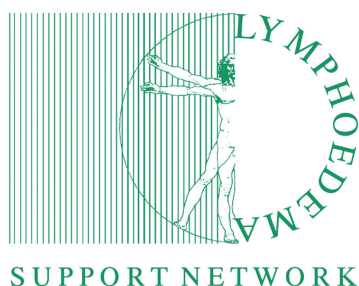
The major thrust of the International Society of lymphology (ISL) at the moment is the 22nd Lymphology Congress which will be held in Sydney with pre- and post-congress sessions in Cairns (Barrier Reef) and Ayers Rock. The detailed programme is available at the website: [www.lymphology2009.com](http://www.lymphology2009.com). This congress, whose themes are based around lymphangiogenesis, lymphatics, lymphoedema and life, brings experts from around the world together with an aim, as an endpoint, to improve patient outcomes. The congress particularly welcomes case studies or innovative and novel ideas so that we may expand our horizon of knowledge. A range of scholarships are available for attendance.

## JAPANESE SOCIETY OF LYMPHOLOGY

The Japanese Society of Lymphology was established in 1988. It now has about 400 active members, involved in the disciplines of anatomy, histology, physiology, pharmacology, immunology, cardiovascular medicine, radiology and surgery. The current president is Professor Toshio Ohhashi, who is a chairman and professor in the Department of Physiology, Shinshu University School of Medicine. The main principle of the society is to develop the field of lymphology combined with cardiovascular medicine, oncology, and innate immunology. In particular, the society is encouraging clinical research into lymphoedema, sentinel lymph node navigation surgery, and lymphatic metastasis of carcinoma cells in Japan. A symposium entitled, 'Lymphangiogenesis and Lymphatic Metastasis of Carcinoma Cells' is currently being organised by the Japanese Society of Lymphology to be held on 27 July until 1 August, 2009 at the 36th International Congress of Physiological Sciences (IUPS 2009) in Kyoto, Japan.



Each year, on 6 March, the NLN and the lymphoedema community nationwide celebrate Lymphoedema Awareness D-Day, a special day set aside to honour inspirational lymphoedema patients: those who have contributed to the community or who have shown great courage in their struggle with disease. On this day, we raise our voices together and say: this is it; we demand treatment, coverage and attention to this condition. In past years, some have been honored at gala events, some in small, intimate gatherings, and others, one-on-one by their health care provider, family or friend. This day provides us with a special opportunity to alert our local media, medical community and neighbourhoods about lymphoedema; to create awareness about the condition, who is at risk, and available treatments, so not one more person will be told they just have to live with it, that nothing can be done. The NLN is a proud supporter of the American Lymphedema Framework Project (ALFP) which was launched in 2008 as a national collaborative initiative in partnership with the International Lymphoedema Framework (ILF) under the leadership of Jane Armer and a core group of multidisciplinary clinicians with a demonstrated expertise in LE serve as the steering committee. The goal of the ALFP is to create and implement a nationally-endorsed standard of evidenced-based best practice for LE within the different service models in the US.



The LSN takes the lead role in educating and supporting patients with this condition. The charity is the largest information resource for lymphoedema in the UK, providing two self-help videos/DVDs and an extensive range of 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. As part of its ongoing work to raise awareness, the LSN is launching a lymphoedema ribbon and wristband campaign, both items bear the words 'Lymphoedema Matters' and will be available throughout 2009 for a suggested donation of £1 per item. Alternatively, patients and healthcare professionals could choose to have a mixed box of items to offer to friends, family and colleagues, again for a suggested donation of £1 per item. For more information please contact the LSN office. In addition, the LSN, the British Lymphology Society (BLS) and the International Lymphoedema Framework (ILF) are currently working together to produce simple to follow guidelines called 'the 5 things you should know about lymphoedema' for GPs, other healthcare professionals, patients and those at risk of developing the condition. The campaign will be introduced on the Healthcare Republic website via an advertorial written and funded by the LSN, and all of the awareness campaign information will be available on the LSN, BLS and ILF websites.

LSN trustees would like to wish the International Lymphoedema Framework Conference every success. For more information visit: [www.lymphoedema.org/lsn](http://www.lymphoedema.org/lsn) or telephone: 0207 351 0990.



The Dutch Lymphedema Network (NLNet) provides a unique forum in the Netherlands for both patients and healthcare professionals involved in lymphoedema and lipoedema. It started in 2000 and offers information and contact details for therapists, regional support groups, as well as a discussion forum. In 2006, NLNet was joined by other leading organisations in the Netherlands involved in lymphology. It facilitates discussion and the exchange of ideas on the internet, enhances public awareness, stimulates multidisciplinary healthcare cooperation and encourages an interest among professional stakeholders. To achieve these goals, there is a HON ([www.hon.ch](http://www.hon.ch)) certified internet website, a journal (*Lymfologica*), regional patient support groups and an annual congress. Membership costs 20 euros per annum, which entitles you to full access to the internet platform and other offers from NLNet. NLNet carry out the national and international guidelines on lymphoedema and are actively cooperating in the development of an European Lymphedema Network ([www.european-lymphologic-network.de](http://www.european-lymphologic-network.de)) and links to other international organisations. For further information please visit: [www.lymfoedeem.nl](http://www.lymfoedeem.nl).



The German Society of Lymphology is holding its 33rd Annual Congress, 'Lymphology — Critical Aspects' on 29–31 October 2009 at Stadthalle, Aschaffenburg. The congress will cover: lymphedema fundamentals; lymphangiogenesis; diagnostic procedures, state of the art; patient management and quality control; lymphoedema treatment (guidelines); obesity problems; MLD in cosmetic procedures. Sessions will include plenary lectures, workshops and a round table discussion with patients. The Presidents of the Congress are Ulrich Herpertz, MLD, Secretary General German Society of Lymphology, e-mail: [drulrich@herpertz.net](mailto:drulrich@herpertz.net) and Oliver Gültig, Senior Instructor MLD/CDT, e-mail: [lymphologic@t-online.de](mailto:lymphologic@t-online.de). For more information, please contact Pia Hermann, Tel: +49 (0)7651/971611; e-mail: [lymphdgl@t-online.de](mailto:lymphdgl@t-online.de); or go online to: [www.dglymp.de](http://www.dglymp.de).



In June 2008 a regional meeting was held in the Conference Center of Rambam Hospital, Haifa, in northern Israel. Approximately 70 lymphoedema patients and physical therapists participated in the meeting, at which 15 new members joined the association. The participants enjoyed lectures and workshops on theoretical and practical subjects, as well as updates regarding innovative garments and bandages, presented by representatives of several companies. The meeting participants, new and long-standing members, also benefited from time spent exchanging ideas and experiences. In July 2008 another regional meeting was held in the Physical Therapy Faculty of Ben Gurion University, Beer Sheva, in southern Israel. This meeting was also very successful and included 50 participants. The Association is presently investing accelerated efforts to finalise the programme for the Fourth National Conference of the Israel Lymphedema Association, which will be held on 3 May, 2009 at the Faculty of Agriculture of the Hebrew University, Rehovot, in central Israel. The programme will include lectures by physicians specialising in vascular surgery, personal stories of lymphoedema patients and practical workshops on self-bandaging and exercise, presented by physical therapists with expertise in lymphoedema treatment. Bob Weiss, a retired space engineer and well known lymphoedema activist, living in California, visited Israel in December 2008 to spend time with his family living in this country. During his busy Israel visit, Bob found time to present results of his studies to the Tel Aviv Lymphedema Support Group, headed by Ayelet Albala, with 40 participants. Bob talked about the differing standards and methods for determination and measurement of lymphoedema and the insufficiency of information available to breast cancer patients to determine, together with their physicians, the optimal method of breast cancer and lymphoedema treatment. He also emphasised the largely neglected increase in cases of breast lymphoedema and the problems in accurate measurement and treatment.



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](mailto: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.

To date there has been increasing emphasis on health promotion and earlier intervention when health problems arise. The Lindsay Leg Club Foundation seems especially well placed in this regard and are determined that its good reputation locally can be levered to create new opportunities. The model has recently caught the eye of the National Institute for Innovation and Improvement, as it has been shown to improve healing and reduce recurrence within a highly cost-effective framework that offers genuine patient choice, delivers public health education and social outreach.



The Foundation has continuously worked in partnership with members of the public, expert patient groups, the Department of Health policy developers, NHS managers and healthcare professionals with an aim to raise awareness of preventative management of all aspects of lower limb related problems. We have also promoted good practice by forging relationships with nursing and professional organisations/societies, patient and industry groups and, in 2008, became an associated member of the European Wound Management Association (EWMA), iLegx and the Knee Foundation.

The Foundation has been selected as a finalist for the 2009 HealthInvestors Award. The HealthInvestor Awards promote excellence and recognise innovation in the healthcare sector; and the judges looked for organisations and individuals that have made an outstanding contribution to the industry in 2008.

The 9th Leg Club Conference will be held over two days at Worcester Sixways Conference Centre on 30th September and 1st October 2009. Programme details will be available shortly on our website: [www.legclub.org](http://www.legclub.org)

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 practise. 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. A number of charity events are planned each year to raise money for Lymfund. Contact MLDUK on 0844 800 1988 or visit the website: [www.mlduk.org.uk](http://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). 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.

The Secretariat of the GAELF is based at the Liverpool School of Tropical Medicine.



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](http://www.lymphoedem.at).