

SOCIETY UPDATE

Historic times for the lymphedema community in the United States

On 23 February 2010 H.R. 4662-Lymphedema Diagnosis and Treatment Cost Saving Act of 2010 was introduced in the House of Representatives by Congressman Larry Kissell of North Carolina. The bill has the goal of reducing total healthcare costs through avoidance of periodic infections, pain and disabilities. Specific goals of the bill are: to provide diagnosis and treatment of individuals with and at risk for lymphedema according to current medical treatment standards, including manual lymph drainage, compression bandages, garments, devices, and exercise; to enhance quality of lymphedema patient care by providing therapist qualification requirements; to provide for lymphedema patient education in the procedures for self-treatment so as to transfer the treatment from the clinical to the home setting; to encourage patient self-treatment plan adherence by providing necessary medical supplies for use at home; to expand patient access to qualified lymphedema therapy by extending coverage to qualified trained lymphedema therapists who may practice under a qualified physician, physical therapist or occupational therapist. This bill was written by NLN Legislative Advocate Bob Weiss. Bob worked tirelessly over the last 10 years and continued to update the bill, then last November Heather Ferguson, a young mother of a three-year-old with lymphedema, convinced Congressman Kissell to sponsor the bill. Before this, Heather was instrumental in securing a bill for treatment in North Carolina. It shows what dedicated lymphedema patient advocates can accomplish.



The British Lymphology Society (BLS) is a medical charity, drawing its members from healthcare practitioners and lymphoedema therapists who are engaged in the treatment of chronic oedema and lymphoedema. The objectives of the society are: to advance education and knowledge in the field of lymphology and related subjects; to foster interest in and co-ordinate a strategy for improving the management of chronic oedema, particularly lymphoedema; to produce and maintain a register of specialist centres in the UK and Ireland; and to benefit patients by improving the knowledge, expertise and skills of healthcare professionals treating them. BLS is a committed supporter of the Lymphoedema Support Network (LSN), International Lymphoedema Framework Project (ILF) and also works in association with Wounds UK to promote awareness of lymphoedema and best practice in its treatment. This year's BLS Annual Conference will be held in Manchester Town Hall from 3–5 October. Conference will highlight the increasing range of disciplines and treatment methods that play a role in the management and treatment of lymphoedema. The keynote speakers will be Dr Andrea Cheville from Mayo Clinic, USA; and Dr Kathryn Schmitz from the University of Pennsylvania. Both will be addressing the conference's key themes: 'Prevention and Provision'.



For information about joining BLS and/or attending the conference: e-mail info@thebls.com, or visit the BLS website: www.thebls.com.



The Global Alliance to Eliminate Lymphatic Filariasis (GAELF) is holding its sixth biennial global meeting in Seoul, Korea from 1st–3rd June, 2010. Details of the meeting including registration form can be found at: http://www.filaria.org/events/registration_form.html.

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.



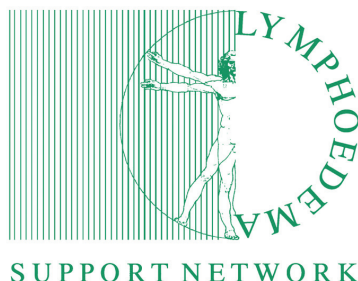
The Austrian LymphLiga (ÖLL) is a non-profit organisation founded in 1994 to provide information and support to lymphoedema patients and healthcare professionals. The ÖLL also endeavours to raise awareness of lymphoedema as an underestimated disease to health authorities, politicians and the general 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. Our next congress will be held in Salzburg on 17th April, 2010. For more information please go online to: www.lymphoedem.at.



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 certified internet website (www.hon.ch), 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 a European Lymphedema Network (www.european-lymphologic-network.de) and links to other international organisations. For further information please visit: www.lymfoedeem.nl.



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 before 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. In mid/late 2010, further updates of the site will occur with details and input of Casley-Smith trained therapists. The LAA website can be accessed at: www.lymphoedema.org.au.



The LSN takes the lead role in educating and supporting patients and is the largest information resource for lymphoedema in the UK. 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 Charity was pleased to be asked by the International Lymphoedema Framework (ILF), to write our 'story' to help inform and encourage international groups who wished to set up their own patient network. This is not to imply that we know it all, always get it right, or that we have completed our work, as none of these things is true. But what is true is that the hard work, dedication and expertise of everyone involved in the organisation since it began in 1991 has seen the LSN grow from a group of just seven members with big ideas, to the UK's leading lymphoedema charity, still with big ideas! A précis of our work has been published as an ILF Focus document and a more complete record of how we have reached this point can be found on our website.

For more information visit: www.lymphoedema.org/lsn; Telephone: 0207 351 0990

Patient support groups have a key role to play in ensuring that patients are sufficiently informed about their condition and the management options available to them. By supporting patients directly with information, we can ensure patients are making informed decision about their care. The Leg Club Foundation now has Trustee representation and plays an active part within the Patients Association Network for Patients, an important initiative founded last year.



The tenth annual Leg Club conference will take place on 29–30th September, 2010 with a line-up of world-renowned, expert speakers, including professors Keith Harding, Helen Edwards and Dr Gregory Shultz. The after dinner speech will be made by The Earl F Howe, Shadow Minister for Health. The Foundation's patron, Professor Christine Moffatt CBE, will give the welcome address. The two-day conference, 'Wound Care in the Noughties: What Changed?' starts with hands-on workshops (involving active participation from corporate partners), followed by main conference speakers on the second day. The event will be held at the Sixways Conference Centre, Worcester. The annual Leg Club conference dinner will take place on the evening of 29th September, 2010 and is expected to mark the tenth anniversary of the conference in style.