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. The website is undergoing updating and change at the moment under the guidance of Professor Neil Piller from the Lymphoedema Assessment Clinic in the Department of Surgery at Flinders Medical Centre. The changes made over the next months will see it developing further into a currently relevant and informative information source about lymphoedema, its causes and treatment, including views on bandaging and garments, as well as essential reference material. The site will 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 professional organisation promoting best practice in lymphoedema management, research and education in Australia and New Zealand. It endeavours to be recognised as an authoritative body that consults with and advises government, educators and health care providers. It promotes evidence-based practice and encourages research in the area of lymphoedema. The ALA launched the National Lymphoedema Practitioners Register (NLPR) in July 2010, a public register of lymphoedema in Australia and New Zealand at: www.nlpr.asn.au. Practitioners fulfil the accreditation and continuing professional development requirements of the ALA. Consumers and health professionals have welcomed this register and now have access to all lymphoedema practitioners working in metropolitan and rural settings across both the public and private sector.

Our biennial conference is planned for 24-26th May 2012 in Cairns, Queensland. The theme of the conference is ‘Hot Topics in Lymphology’ and we are pleased to have Professor Peter Mortimer as keynote speaker. The ALA encourages international colleagues to join us in Cairns for an innovative and thought-provoking programme in an exciting and relaxed setting. Detailed information is available at: www.alaconference.com.au.

At the ALA Annual General Meeting in May 2011, an announcement of inaugural education and research scholarships will be made.

The Israeli Lymphedema Association was established in 2004 as a non-profit organisation to promote lymphoedema awareness and offer support to people living with lymphoedema. Close to 600 people have made contact with the association and the current paid membership is 150. Support groups meet regularly in various parts of the country. Ayelet Albala, a veteran support group coordinator is presently running three support groups in conjunction with a lymphoedema practicing physical therapist for each group. In addition, Ms Albala advises less experienced coordinators. A special support group has been established for people with primary lymphoedema and is directed at young people and their parents. The support groups are run on a voluntary basis by all involved.

Planned for 2011 is the biannual Israel Lymphedema Conference for Patients and Therapists held at the Jerusalem University Campus in Rehovot. The updated version of the ILF Consensus Document will be translated into Hebrew assisted by a donation from Martin and Lorraine Rabinowitz from the USA. Committee members will be meeting during the year with representatives of the HMO’s to discuss the present lymphoedema treatment provision for their members and to seek solutions for shortcomings.

July Levy, a committee member, has been in contact with Lymphedema Associations in different countries. We would like to see these ties strengthening as we are aware of our limitations and feel that we can improve our activities by learning how others are dealing with similar issues.

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2011 began with the launch of an updated Mission Statement which is a truer reflection of our work and now reads: ‘The Lymphoedema Support Network represents, supports and empowers people affected by lymphoedema, promotes awareness of the condition and campaigns for appropriate, equitable treatment for all. Two new fact sheets will be launched in the spring, ‘Lipoedema’ and ‘Management of Oedema in Advancing Disease — Information for Patients’ and our website www.lymphoedema.org will soon include a section aimed at healthcare professionals, written for the LSN by Dr Vaughan Keeley. We are delighted to be working with the Royal College of Nursing on producing guidelines for nurses caring for those ‘at risk’ of developing, or living with lymphoedema. We also welcome Mr Matthew Waltham MA PhD FRCS to our medical advisory team. Mr Waltham is Senior Lecturer, Vascular Surgical Science and Honorary Consultant Vascular Surgeon at St Thomas’ Hospital, London and, like our other team members, will be there to ensure that our information is accurate and a true reflection of current best practice. Perhaps most exciting of all, the LSN has commissioned a lymphoedema module aimed at general practitioners from BMJ Learning which it is anticipated will be launched in the Autumn. The rest of 2011 looks as if it is going to continue at the present frantic, but productive rate for the LSN.
The benefits of compression therapy when treating chronic venous insufficiency and leg ulcers is well documented and widely accepted as the gold standard. Incorporating the three Stemmer signs into the Leg Club initial assessment documentation as a diagnostic tool has enabled clinicians to ensure appropriate management for Leg Club members. However, it has also identified a need for further education in this specialised area. Until recently, limited guidance has been available for professionals treating patients with varying degrees of chronic oedema. Leg Club may be the first point of contact for many patients and thus plays a pivotal role in enhancing opportunities for early treatment and specialist referral. The Foundation and community nursing teams are addressing the need to embrace this complex challenge through education and building relationships with lymphoedema nurse specialists and other professionals. Both toe bandaging and the management of chronic oedema are being addressed in workshops held on the first day of our Leg Club conference, ‘Wound Care: Issues of Everyday Practice’ at Worcester Rugby Club on 28-29th September, 2011.

Since our last update, the Foundation is pleased to announce that it has entered into a partnership with RAFT – The Restoration of Appearance and Function Trust, an excellent example of two organisations working together at grassroots level to improve outcomes for patients. RAFT is an independent charity carrying out pioneering research into practical and affordable ways to save and repair skin. The partnership will see the two charities combine their strengths, with the ultimate aim of providing a better quality of life for patients with leg ulcers.

For information about the Leg Club conference contact Lynn Bullock at: lynn@legclubfoundation.com; telephone 01728 862093, 07771 962021, or visit the website: www.legclub.org.

The NLN is exceptionally busy this year and are thrilled to share some of their recent programmes and activities. On 6th March 2011 we celebrated our 17th Lymphedema D-day. Every year, we recognise extraordinary LE patients for their courage and strength, the impact their advocacy has on local communities, and the therapists and doctors who provide exceptional care to patients and contribute to the growth of this field. Lymphedema D-day has grown globally, spreading awareness about lymphoedema in other countries.

Through the work of the NLN Medical Advisory Committee, lymphoedema standards are now included in the National Accreditation Program for Breast Centers (NAPBC) in the US; the first time lymphoedema has officially been included in accreditation requirements. These standards include: pre- and postoperative bilateral arm measurement, education in risk reduction practices, and NLN measurement guidelines. Presently, there are 400 accredited breast centres in the US. For more information: www.accreditedbreastcenters.org.

The NLN position paper on ‘Diagnosis and Treatment of Lymphedema’ has also been updated to include new information and research regarding lymphoedema care. The full paper can be viewed on the NLN website.

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.filariasis.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 F. pinipaludis 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 ÕLL also endeavours to raise awareness about 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 biannual national congress for healthcare professionals is also organised by the ÖLL to promote interdisciplinary collaboration and to provide the latest update on lymphology research. For more information: 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 (Lymphologica), 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 German Society of Lymphology (DGL) has existed since 1976, developing as an offshoot from the Society for Manual Lymph Drainage (Dr.Voedder) and Related Therapies (GIMLV) that was founded in 1967. It is a membership organisation, recognised as a non-profit society. The goal of the society is to promote research and teaching in the field of lymphology. The DGL works with professional organisations, government agencies, health organisations, support groups, patient organisations and other medical societies both nationally and internationally. Since 1999, the three independent german-speaking societies have re-established links to support one another and drive forward awareness and education of lymphoedema.

On 23–25th June, 2011 there will be a joint meeting between the DGL and GDL (German Speaking Society of Lymphology) in Goettingen, Germany. The main topics under discussion include the pathobiology of the lymphatic system, lymphogenic ways of metastases and breast reconstruction in lymphoedema. Sessions will include plenary lectures, workshops and a discussion with patients. For more details please visit the homepage: www.lymphologie2011.uni-goettingen.de

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. The examination is given semi-annually and is administered by Schroeder Measurement Technologies (SMT). To date, we have certified over 1,000 therapists.

Visit the LANA website, www.clt-lana.org for more information about LANA and the certification examination. If you wish to contact LANA for additional information, please feel free to email LANA at lana@clt-lana.org or contact LANA by phone at: 773-756-8971. Our mailing address is LANA, PO Box 466, Wilmette, IL, 60091 USA.