

AUSTRALASIAN LYMPHOLOGY ASSOCIATION (ALA)

Christine Smith

The Australasian Lymphology Association (ALA) strives to promote excellence in all aspects of lymphoedema and other oedemas across Australasia. From primary to secondary lymphoedema, paediatrics to geriatrics, from the genetic development of the lymph system, to clinical-based assessment and treatment, the ALA has been instrumental in the recognition of this condition. Areas including education, committees associated with the development of assessment standards, subjective and objective assessment and those to do with the lymphoedema workforce have been just some areas of work achieved by the ALA.

Key words

International associations
Working parties
Project involvement
Subcommittees

Internationally, Australia contributes proportionately to the lymphoedema community. In a literature review spanning from 2000 to 2007, six out of 26 natural history studies were from Australia (Newman, 2008). In the relatively short time since its inception, the Australasian Lymphology Association (ALA) has and continues to promote the development of lymphology in Australasia.

Background

In 1994, Beiersdorf invited lymphoedema experts from each state of Australia to a meeting in Sydney, to discuss issues facing lymphoedema practitioners across the nation. Invitation was by means of the lymphoedema support groups in each state.

Christine Smith is Senior Physiotherapist, Lymphoedema/Oncology, Royal Perth Hospital, Perth, Australia

This meeting included those professionals recognised for their promotion of, development and research in the area of lymphology, both in Australia and in the international lymphoedema community. Participants were Judith and John Casley-Smith, Jacqui Hamilton, Sandra King, Michael Mason, Bev Mirolo, Maree O'Connor, Neil Piller Hildegard Reul-Hirche and at a later date, Jenny Bartley from New Zealand.

This initial meeting gave rise to the formation of a steering committee which proposed the establishment of the ALA. In 2000 this committee became the ALA. In 2000–2001, there were 125 ALA members. From this time there has been a steady increase in membership numbers to 250 current members. All states and territories have members, including a member in Canada. Physiotherapists have the largest representation (137), followed by registered nurses, massage therapists and occupational therapists. A broad range of professionals contribute to the membership of the ALA, including doctors, a pathologist, social workers, researchers and others.

Vision and objectives

The vision of the ALA is to make a difference in all aspects of lymphology.

The ALA is committed to achieving and promoting excellence in all aspects of oedema and lymphoedema across

Australasia, through advocacy and the sharing of information and knowledge.

The objectives of the ALA are:

- ▶▶ To promote evidence-based practice in the prevention, detection, diagnosis and management of lymphoedema and other oedemas
- ▶▶ To be recognised as an authoritative body that consults and advises government, educators, healthcare professionals and other third parties in lymphoedema and other oedemas
- ▶▶ To provide and promote a forum for the regular exchange of views and information in relation to lymphoedema and other oedemas
- ▶▶ To encourage research in the area of lymphoedema and other oedemas
- ▶▶ To assist and promote a high standard of professional practice and member behaviour.

The ALA council is responsible for the day-to-day management of the ALA. The council consists of healthcare professionals and a consumer representative. It has developed a number of subcommittees to assist the organisation in achieving its objectives. Subcommittee areas have included governance, a newsletter, marketing, training guidelines, assessment and measurement and compression garments. All participants volunteer their time to further promote and develop lymphology in Australia.

Education

The importance of keeping members up to date with the development of the ALA and abreast of national issues became apparent. To this end, the first newsletter was published in February 2000. Initially these newsletters were compiled from start to print by the ALA secretary, Jacqui Hamilton.

Clerical assistance with membership and the newsletter was instigated in 2003. There are now three editions published per year. The newsletter keeps members updated on ALA activities and contains information on medical issues related to lymphoedema, feature articles, a president's report, subcommittee reports, state and territory reports, protocols, news, upcoming events, lymphoedema-related products, courses and research (both in Australasia and internationally).

Biennial conferences started in 1996. The aims of the conferences are to provide and promote a forum for the regular exchange of views and information in relation to lymphoedema and other oedemas.

Conference management has developed as the ALA has grown. In 1996 the conference was completely organised by the ALA steering committee. In 1998 the steering committee had assistance with registration handling only, and in 2000, when the ALA became a company, a conference event organiser was engaged. A conference event organiser continues to assist the conference organising committee with the task of arranging the biennial events.

International keynote speakers have included Professor Terrence Ryan, Professor Peter Mortimer, Professor Ethel Földi, Professor Albert Leduc, Doctor Jacquelyne Todd and most recently Associate Professor Kathryn Schmitz. Topics from these keynote speakers have included the anatomy and pathophysiology of the lymphatic system, the prevalence and incidence of lymphoedema, lymphoedema training and education and exercise. Delegates from across Australia, New Zealand and Asia attend these conferences. The latest conference was held in Fremantle,

Western Australia attracting 200 delegates.

In 2000 the ALA entered into a reciprocal agreement with the British Lymphology Society (BLS) to encourage cross-Commonwealth conference attendance. The official policy related to this was endorsed in April 2005. This reciprocal agreement funds the conference registration of up to two ALA members to attend the BLS conference and vice versa.

The ALA website was launched in 2003 in Brisbane. This professionally-based site was designed to provide an electronic face for the ALA. Information about upcoming events, contact for the committee, promotion, development and resources, including ALA standards and guidelines can be found on this website at www.lymphology.asn.au.

The website was redesigned in October 2009 to reflect the ongoing promotion and development of the ALA and lymphology in Australasia. The website is the electronic resource of the ALA designed for both healthcare professionals and consumers.

Tertiary lymphoedema training

The ALA education and training guidelines subcommittee (ETGS) was established in 2006. This subcommittee aims to develop a national tertiary based, accredited multidisciplinary lymphoedema management and training programme.

A graduate certificate in lymphoedema management is being developed that will have the ability to be delivered in each state and overseas. The advantages of a certificate programme is that it is less time and financially demanding on participants, yet has the ability to progress to a Masters degree. The ETGS are currently developing the first part of the graduate certificate which is the Specialist Certificate in Lymphoedema Management. This certificate will be more comprehensive than current level 1 courses provided in Australia and New Zealand.

The ETGS has received excellent input from the centre for Medical and

Health Sciences Education at Monash University regarding learning outcomes. The next step is to develop the content for each learning outcome. Previous work by the BLS to standardised course content has been of invaluable assistance for this subcommittee. The ETGS is applying for funding to assist with course development. Work on this project continues.

Committees, assessment standards

Objective assessment

The measurement standards subcommittee developed a national standard for upper and lower limb circumferential measurements.

The aim was to determine a national standard for the measurement of lymphoedematous limbs that could be used by clinicians and researchers. Standard measurement procedures would encourage quality of services to consumers and accountability. Having a national standard would allow comparability for research, collaboration and ensure consistency in approach for consumers.

The process of measurement standards determination has been gradually progressing since 1996. There were several stages of consultation with lymphoedema clinicians.

The issues were first recognised as a priority by a group of Australian experts involved in a consultative process facilitated by Neil Piller. This group was assembled to inform the ALA of the major issues and concerns of lymphoedema therapists. Twenty-six experts took part and identified many major domains of concern relating to training, education, treatment and measurement standards. The area where there was the strongest agreement, at least 80% respondents, was that there was a need for rapid action relating to the determination of standards in assessment, particularly relating to the ways in which limbs were measured.

The issues of standards were raised at the second ALA Conference in Brisbane in 1998. At this stage much discussion occurred about the role and function

of standards and the framework for the standards committee was determined.

At the April 2000 third ALA conference in Melbourne, a standards determination session was held with 90 participants. Participants indicated their preference and reasons for current practices and results were tallied. This process revealed that the ALA was already well on the way to developing strong agreement on measurement. Further comments and discussion occurred. A debate of the key issues that had arisen from the 2000 conference was held by attendees at the ALA annual general meeting in Sydney in April 2001. At the 2002 conference a vote was held on each issue and the results of this session were published in the ALA newsletter.

A summary of the changed and current measurement forms were printed in the November 2003 ALA newsletter. The measurement forms are accessible on the ALA website.

Subjective assessment

Continuing with the objectives of the measurement subcommittee to provide a more standardised approach to gathering client data, is the development of a lymphoedema subjective assessment form.

This process started in November 2006 with a call for submissions. By March 2007 a literature review was conducted and larger lymphoedema treatment centres in Australia and New Zealand were extended an invitation to share their assessment forms. Only larger centres were invited due to time and resource constraints, however all other lymphoedema therapists were encouraged to participate.

By comparing existing forms and taking into account the most frequently required information, the aim was to combine all necessary information on one form. As for the measuring standard, a consultation process was undertaken with ALA members and other stakeholders. The eventual aim being to display the form/s on the website for every lymphoedema therapist to download free of charge.

By November 2007 there were nearly 30 assessment forms received by the measurement subcommittee. Many of these forms dealt with all forms of lymphoedema — primary and secondary, including breast, neck and head.

The subcommittee collated all this information and different assessment formats were discussed. Draft forms were posted on the ALA member-only part of the website, with a call for feedback from November 2007. Feedback received was incorporated into these forms. A draft of this was presented at the ALA conference in Fremantle in 2008. The work to provide a national standard for assessment continues.

Lymphoedema workforce

ALA lymphoedema national service equity survey

In 2002 the ALA lymphoedema national service equity survey documented lymphoedema services in Australia. It surveyed lymphoedema practitioners regarding service and garment provision, and identified current lymphoedema service providers and the inequity in service provision. This survey has been quoted in a number of national and state-based lymphoedema project reports.

National lymphoedema practitioners' register

In 2007 the ETGS also started developing the guidelines to establish a national lymphoedema practitioners' register (NLPR). A dedicated NLPR subcommittee was formed in August 2008 to continue working on this project. The lack of a publicly available resource of appropriately trained and accredited lymphoedema practitioners for healthcare professionals and consumers drove the necessity for this register:

The ALA NLPR will include both lymphoedema practitioners in Australia and New Zealand.

The proposed objectives of the NLPR are:

1. To assist in the maintenance and promotion of professional standards of practice for lymphoedema management throughout Australia and New Zealand.
2. To provide a registration and re-registration process for an individual

to be listed on the NLPR.

3. To maintain a current register of lymphoedema practitioners.
4. To distribute the register to healthcare professionals, consumers, health insurance companies, compensable bodies and other interested persons via the ALA website to enable them to access appropriately qualified lymphoedema practitioners.

The envisaged benefits of the NLPR are:

1. To facilitate the maintenance and promotion of professional standards of practice for lymphoedema management throughout Australia and New Zealand.
2. To enable healthcare professionals, consumers, insurance companies, compensable bodies and other interested persons to access lymphoedema practitioners throughout Australia and New Zealand.
3. To assist lymphoedema organisations, consumers and lymphoedema therapists to lobby for better health insurance rebates for lymphoedema treatment.
4. To enable the ALA to provide government bodies with current information on equity of access to lymphoedema treatment.
5. To provide the opportunity to encourage collaborative lymphoedema research and obtain a better understanding of the prevalence of lymphoedema in both Australia and New Zealand.

The NLPR guidelines were voted on and overwhelmingly agreed to at the ALA special general meeting coinciding with the International Society of Lymphology (ISL) conference in September 2009. A dedicated multidisciplinary group set about the onerous, difficult and at times challenging task of developing the NLPR guidelines.

Compression garment subcommittee

The compression garment subcommittee was formed in 2002 following the release of the ALA lymphoedema service equity report. The role of this subcommittee is to assist in raising issues and providing

information related to garment availability and accessibility for clients. Ongoing issues that consistently arise are equitable assistance with provision of compression garments and national standards in regards to compression garment quality.

Early in 2009, ALA members were surveyed in regards to their use of compression garments as a part of their treatment of lymphoedema. The aims of this survey were to give a snapshot of Australian lymphoedema practice, identify the similarities and variance in practice around Australia and how the association could use this information to assist clients.

The responses have been summarised. The subcommittee presented their preliminary findings with a poster at the International Society of Lymphology Congress in Sydney, 2009. Areas identified as requiring further research include funding for garments across different states and services, and clear guidelines for prescription, measuring and fitting of garments.

Cellulitis management consensus document

In 2006 the ALA medical advisor along with a number of medical practitioners began work to develop an Australian consensus document of the management of cellulitis in lymphoedema. This document needed to be consistent with current Australian Antibiotic Therapeutic Guidelines and was completed in June 2008. It is available on the ALA website.

Involvement/participation/representation

As part of the ALA's objectives to promote the development of lymphology, the organisation has provided representation on a range of lymphoedema projects. These have included:

- ▶ 2000: National Lymphoedema Summit, Adelaide. Encouraging research into lymphoedema. Funded by the then Commonwealth Department of Health and Aged Care, in association with the National Breast Cancer Council (NBCC) and the Office of the Status of Women
- ▶ Outcome of the Summit: 2001 lymphoedema research grant funded by the Commonwealth Department of Health and Aged Care, titled

'Developing Strategies for the Measurement of Limb Morbidity and Lymphoedema'

- ▶ 2001: Primary and secondary lymphoedema — priorities and strategies workshop, Melbourne. Funded by the Australian Government
- ▶ 2002: ALA Lymphoedema National Service Equity Survey
- ▶ 2003: A review of lymphoedema services in Victoria. Funded by the Victorian Department of Human Services
- ▶ 2004: Review of current practices and future directions in the diagnosis, prevention and treatment of lymphoedema in Australia. Report to the Australian Health Minister's Advisory Council
- ▶ 2004: Lymphoedema workshop at the Breast Cancer Network Australia's (BCNA), 'Still making a difference' conference
- ▶ 2006: The consumer-based Lymphoedema Association of Victoria (LAV) obtained a Victorian Government grant to provide an education programme to general practitioners on both primary and secondary lymphoedema
- ▶ 2007: NBOCC Secondary Lymphoedema Initiative. Funded by the Commonwealth Department of Health and Aging
- ▶ 2007: Cancer Australia: Quality and Professional Development National Advisory Group
- ▶ 2008: Review of research evidence on secondary lymphoedema: incidence, prevention, risk factors and treatment, Dr Sandi Hayes
- ▶ 2008: Lymphoedema Following Breast Cancer Think Tank. Funded by the National Breast Cancer Foundation
- ▶ 2009: International Lymphoedema Framework (ILF) Conference, Ascot
- ▶ 2009: ILS Congress. This was an exciting year for lymphology in Australasia as, for the first time, our region hosted the 22nd International Society of Lymphology Congress in Sydney with additional meetings at venues in Cairns and Alice Springs.

Charitable status

In 2008 the ALA was given official notification of its new charitable

Key points

- ▶ The ALA is the peak professional organisation promoting best practice in all areas of lymphology in Australasia.
- ▶ The association continues to develop its national and international affiliations as a multidisciplinary group dedicated to providing lymphoedema management, research, advocacy, education and training.
- ▶ The ALA continues to strive for the promotion of lymphology in Australia.
- ▶ The recognition of lymphoedema is testament to the tireless and predominantly voluntary work of the ALA's founders and committee members.

status which enables the ALA to be a tax deductible gift recipient. This fund will be used for the purpose of prevention, detection, diagnosis and management of lymphoedema and other oedemas by providing research grants, scholarships and education for healthcare professionals, individuals with lymphoedema and the general public.

The ALA has and continues to strive for the promotion of lymphology in Australia and improvement in the management of those with, or at risk of developing lymphoedema. The recognition of lymphoedema by individuals, government, health authorities and educators, both nationally and internationally, is testament to the tireless and predominantly voluntary work of its dedicated founders and current committee members. JL

Reference

Newman B (2008) Where do we stand — update from a systematic review of the lymphoedema literature, presented at Lymphoedema Following Breast Cancer Think Tank, Brisbane, 27 November 2008