

New partnerships, new strengths, and improved professional awareness and patient outcomes

Neil Piller

The identification, treatment and management of all forms of chronic oedema (lymphoedema) requires a multidisciplinary approach. We have no doubt there are many deficiencies in our knowledge, even our basic knowledge, such as what we understand about the incidence and prevalence of lymphoedema, our professional knowledge of it, the ways it impacts on patients and the ways we can better inform industry of the needs of our patients (to optimise outcomes), as well as the strategies that governments and health funds need to develop to support new knowledge.

As clinicians and allied health professionals, we should use the knowledge we acquire to become proactive rather than reactive in all aspects of the recognition and treatment of lymphoedema. The sharing of information, improving communication between groups and improving knowledge-sharing between countries within and between countries in the developing and developed worlds are all good ways of plugging this knowledge gap.

To facilitate this, the International Lymphoedema Framework (ILF), *Wounds UK* and the *Journal of Lymphoedema (JOL)* have joined together in an alliance. *JOL* aims to improve the dissemination of knowledge about education, diagnosis, practice development, and research and audit. The ILF also aims to improve the management of lymphoedema and related conditions worldwide through raising the profile of lymphoedema internationally through its meetings and nationally through the establishment of National Lymphoedema Frameworks (NLFs). An ambition of the ILF — which is already being achieved — is to place lymphoedema and its management as a priority on national healthcare agendas through the provision of an international global minimum dataset to enable clinicians

to better lobby for improved financing and reimbursement of all aspects of lymphoedema care, as well as to help address the current inequity in services provision. The ILF is unwavering in its belief that lymphoedema services be based on best practice and consensus documents, a number of which have already been created and appear on the *Wounds UK* website.

In addition, the ILF aims to facilitate the creation of a lymphoedema community who together, both locally and internationally, strive to improve the evidence base for treatment and professional practice.

Many national lymphoedema frameworks have already been established, including those in Canada, the USA, the UK, Australia, Denmark, France and Spain, while others e.g. the Netherlands, Belgium, Italy and China, are in the process of formation. Each framework undertakes a specific task in terms of knowledge improvement that can then be used to improve local outcomes but which also has international relevance.

A major overall focus of the ILF and a number of national frameworks, such as the Australian one at the moment, is on the LIMPRINT study, the aim of which is to develop a toolkit for use by NLFs to determine the number of people with chronic oedema and to assess its impact on individuals and healthcare systems.

An ILF aim is to facilitate improved links with industry. With these, we hope there can be a greater focus on product innovation, and new approaches to diagnosis; the intention is that this will lead to improved patient outcomes.

The ILF and this journal seek to listen to you as authors, potential authors and readers. There is little good in undertaking quality work unless it is published and presented in an appropriate forum, whether at a national or international meeting or in a journal, such as ours. Those who undertake the research must have a conduit to those with lymphoedema or those who are helping patients manage or are treating it.

JOL represents an opportunity for translational research, linking research with the ward, the bedside and the patient's world. This can be evidenced by the fact that *JOL* receives and publishes articles directly from patients, found in the Patient Perspective section. What good is even the best research if it is not applicable to practice and if we don't know what patients actually want or need? As an example of this, glance back at a prior editorial, entitled "We need to help patients help themselves" (Piller, 2012) and a subsequent response by a very well informed patient "Non Compliance: It's Easy for You to Say" (Dart, 2012). This, as an example of two-way conversation, does make a difference, not only between clinicians and patients, but between clinicians and industry, and clinicians and governments and health agencies.

We all need to communicate better and we hope this link between the ILF, its national frameworks, its industry partners and *JOL* helps better achieve our collective aims. Showing the value of patient input (and the patient is central to the aims of the NLF), was a parting comment by Dart (2012), suggesting a spray-on, breathable compression garment (one she could just peel off when not longer needed) as one solution to her problem!

As part of our bid to improve lymphoedema education and awareness, in May 2016 we are holding the Asia Pacific Lymphology Congress in Darwin, Australia, which is integral to highlighting the issues facing developing countries, but it's also about the sharing of ideas and moving forwards.

We look forward to your contributions to our journal and hope this new link helps all of us make a collective difference, both locally and globally.

References

- Dart L (2012) Non compliance? It's easy for you to say. *Journal of Lymphoedema* 7(1): 8
- Piller NB (2012) We need to help patients to help themselves. *Journal of Lymphoedema* 7(1): 6

Neil Piller is Director Lymphoedema Research Unit, Department of Surgery, School of Medicine, Flinders University, Adelaide, South Australia, Australia.