

# MOVING FORWARD WITH THE AMERICAN LYMPHEDEMA FRAMEWORK PROJECT (ALFP)

Jane Armer, Joe Feldman, Janice Cormier

We are moving ahead in year two of the three-year National Library of Medicine G08 grant on Cyber Informatics Tools for Lymphoedema Stakeholders which enables us to develop and build the infrastructure for the American Lymphoedema Framework Project (ALFP) lymphoedema minimum data set (MDS). The ultimate goal is to create an operational cyber infrastructure that collects, organises, and disseminates up-to-date information to lymphoedema stakeholders. Five US clinical and research data sets are in hand for beta-testing the infrastructure, and arrangements are being made to accept several additional national and international data sets. Queries on participating in the MDS are welcomed from research and clinical partners around the country and internationally.

## Systematic reviews

Completion of the systematic reviews in twelve topical areas associated with the content of the first Best Practice Statement are moving forward. This is being led by 25 co-authors/expert clinicians and researchers across disciplines, supported by the ALFP staff and executive committee.

The first two systematic review manuscripts (surgery and exercise) are now published (Cormier J, Rourke L, Crosby M, Chanag D, Armer J. The surgical treatment of lymphedema: A systematic review of the contemporary literature (2004–2010). *Ann Surg Oncol*.

Jane Armer is Director; Joe Feldman is Co-Director; Janice Cormier is a Member of the Executive Committee, all for the American Lymphedema Framework Project (ALFP)

Doi 10.1245/s10434-011-2017-4; Kwan M, Cohn J, Armer J, Stewart B, Cormier J. Exercise in patients with lymphedema: a systematic review of the contemporary literature. *J Cancer Survivorship*. doi 10.1007/s11764-011-0203-9). Both updates were presented as part of plenary sessions at the 2011 International Lymphedema Framework (ILF) conference in Toronto, Canada, in June 2011 and the 2011 International Society of Lymphology Congress in Malmo, Sweden, in September 2011. A third manuscript (self-management) is in press and a fourth is in review. The other manuscripts are in development and near-final drafts for review are anticipated shortly.

## ALFP meeting

The ALFP held a meeting at the 2011 ILF conference in Toronto in June, which comprised various lymphoedema stakeholders including researchers, healthcare professionals, industry partners, ALFP steering committee members, and ALFP international advisory board members. The meeting highlighted the activities and future plans of the ALFP, particularly focusing on the systematic reviews and MDS development, and soliciting input from stakeholders on prioritising the next steps forward.

Nine members of the ALFP steering committee participated in the ILF National Frameworks pre-conference sharing and planning day. Each framework made a 10-minute presentation to update the other framework members on their progress, and met in break-out sessions on topics such as the MDS, best practice statement, education, and so on.

## ALFP presentations:

Jane Armer presented on the ALFP systematic review and Best Practices update at a plenary session with Christine Moffatt, ILF director, and Deborah Doherty, medical writer for the Best Practice Statement.

Chi-Ren Shyu, principal investigator on the G08 grant, presented an update on the development of the ALFP MDS, followed by a presentation by Nancy Hutchison, Medical Director for Cancer Rehabilitation and Lymphedema, Sister Kenny Rehabilitation Institute, Virginia Piper Cancer Institute, Allina Health System, on her decision to collaborate in the MDS development and the subsequent benefit for her institution.

Other presentations included the findings of the ALFP therapist survey in both a poster and a moderated poster session at the Oncology Nursing Congress in Boston in April by Jane Armer. She was also interviewed by two media sources on the ALFP and the therapist survey results.

Jane also presented on the ALFP mission, goals, and progress in international nursing, oncology, and lymphedema meetings in Thailand (March), South Africa (May), and Germany (June).

Through partnership with many stakeholders, the ALFP continues to move forward in increasing awareness and improving care for people with lymphoedema and related lymphatic disorders. JL

Any enquiries for the ALFP, please email: [alfp@missouri.edu](mailto:alfp@missouri.edu).