American Lymphedema Framework Project

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Mission

The American Lymphedema Framework Project (ALFP) is a national initiative developed under the leadership of recognized clinical experts and investigators in the field of lymphedema. A collaboration of healthcare providers, researchers, patients, and industry representatives, the ALFP will develop and evaluate appropriate health care services for patients with all forms of lymphedema and advance the quality of lymphedema care both in the United States and worldwide. To move this charge forward, the ALFP has formed a partnership with the International Lymphoedema Framework (ILF), a UK-based research partnership founded in 2002, which has made tremendous strides in raising the profile of lymphedema and improving the standards of care in Great Britain.

The mission of the ALFP is to improve the management of lymphedema and related lymphatic disorders in the United States while contributing to global international improvement in this field. This will be achieved by defining best practices and developing a minimum data set to improve lymphedema outcomes. The ALFP will establish a leadership role in lymphedema risk reduction, treatment, education, health policy, and research. These outcomes will be achieved through a partnership among all lymphedema stakeholders.

Goals

- Revise and update a Best Practices Document for lymphedema care in the U.S.
- Develop and implement a lymphedema minimum data set for clinical and research use nationally and internationally.
- Design a U.S.-based epidemiology protocol to determine the size and complexity of the problem of lymphedema from all causes (primary and secondary lymphedema).
- Develop methods for evaluating patient-based outcome measures and improving patient outcomes.
- Develop and provide appropriate practice-based lymphedema educational programs.
- Contribute to the mission and goals of the ILF.
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Minimum Data Set (MDS)

A major goal of the ALFP is to collaborate with the ILF and other national frameworks in the development of the MDS for clinical and research use nationally and internationally. The MDS will be used to evaluate patient-based outcome measures worldwide. Methods of data collection have been developed, including the design and testing of an internet-based information technology system under the oversight of Dr. Chi-Ren Shyu, Director of University of Missouri Informatics Institute, to serve as a platform for the collection and transfer of data.

The ALFP is moving the international lymphedema MDS forward with development of the database architecture and beta testing the integration of de-identified data sets from multiple clinical and research sites. Progress in the MDS development is being made with support of the recently funded National Library of Medicine G08 grant on Cyber Informatics Tools for Lymphedema Stakeholders (2010-2013).

There are eight development modules in this project in a prioritized order:

1. Building a data warehouse for a minimum data set (MDS) and data governance protocols for cross-institutional studies.
2. Developing survey and analysis tools for each stakeholder group.
3. Computationally collecting high quality and evidence-based knowledge from a selected set of lymphedema (LE) organizations, journals, and news releases from reputable public media.
4. Constructing an informatics tools library for mining structured and unstructured information sources, performing statistical tests, and creating graphics/figures for information visualization.
5. Building a case-based library for complex case repository and exchange within and across stakeholder groups.
6. Building a knowledge base for indexing discovered patterns from all information sources and linking it with the Best Practices guidelines.
7. Developing user-centered query methods dedicated for patients/families, health professionals, health educators, and researchers.
8. Monitoring the proposed work by quantitatively and qualitatively measuring the improvement of research/clinical outcomes and LE awareness.
Best Practice Document & Systematic Review

A major goal of the ALFP is to collaborate with the ILF in the development of a second edition of the ILF Best Practice Document, as well as adapt the document for lymphedema management specific to the United States. A preliminary review of gaps and updates to the 2006 ILF Best Practice Document was completed in 2009 by expert clinicians for application to the health care delivery system in the U.S. and worldwide.

In 2010, as part of this goal the ALFP also completed a systematic review of lymphedema literature from 2004-2009 under the guidance of an experienced research librarian using the UK BPD search terms and exploded terms. The systematic review topics can be seen in Table 1.

**Databases Searched:**
The databases searched were PubMed-Medline, CINAHL, Cochrane Database of Systematic Reviews, Cochrane Controlled Trials Register, PapersFirst, ProceedingsFirst, Worldcat, PEDro, National Guidelines Clearing House, ACP Journal Club, and DARE.

**Literature Review Methods:**
1. **Initial screen (2004-2009)** by research librarian that general inclusion criteria were met.
2. **Screen 1** – Article titles and abstracts reviewed by research associate for general applicability to lymphedema.
3. **Screen 2** – Editors sorted literature from Screen 1 into included and excluded articles and topical areas.
4. **Screen 3** – A review of the full text articles from Screen 2 by the topic experts for inclusion or exclusion.

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<th>Table 1. Systematic Review Topics</th>
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<td>• Assessment</td>
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<td>• Risk-reduction</td>
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<td>• Complete Decongestive Therapy</td>
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<td>• Exercise</td>
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<td>• Surgical approaches</td>
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<td>• Intermittent pressure devices</td>
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<td>• Other treatments</td>
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<td>• Complex cases</td>
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<td>• Wound and skin issues</td>
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<td>• Palliative Care</td>
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<td>• Living well with LE</td>
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<td>• Psychosocial issues in LE</td>
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<td>• Economic/health policy issues</td>
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Additional articles were nominated by topic experts for inclusion or exclusion, and articles from 2010 and 2011 were also included, as appropriate. Lymphedema case series were included, if cases were ≥10. Gray literature, non-refereed articles, abstracts, and dissertations were excluded.

Topic experts categorized evidence using the research grading system from the Oncology Nursing Society (ONS) Putting Evidence into Practice (PEP) level of evidence guidelines\(^1\) or alternative rigorous categorization. PEP level of evidence categorization was applied by consensus among topic authors and confirmed by editors.

The ALFP will produce a series of lymphedema manuscripts for publication in 2011 and 2012 and will provide summaries of the systematic review for incorporation in the update of the Best Practice Document (second edition).


Systematic Review
Publications, Presentations, Posters, & Grants

**ALFP Publications**


**ALFP Presentations**


ALFP Posters


ALFP Exhibits

ALFP Exhibit (2010, March). Exhibit at the 2nd International Lymphedema Framework Conference, Brighton Centre, UK.

ALFP Exhibit (2010, September). Exhibit at the 9th National Lymphedema Network Conference, Orlando, FL.

Grants


NLN 2010 Conference
Acknowledgements

On behalf of the American Lymphedema Framework Project team, our Executive and Steering committees, and all our existing stakeholders, we are deeply grateful for the support provided by the American Cancer Society, through The Longaberger Company, a direct selling company offering home products including handcrafted baskets made in Ohio, and the Longaberger Horizon of Hope Campaign, which provided a grant to the American Cancer Society for breast cancer research and education. This support has significantly helped move forward the mission and goals of the ALFP.

The ALFP Executive Committee: Janice Cormier, Joseph Feldman, Christine Moffat, and Jane Armer, with the 2009 Longaberger Horizon of Hope Basket, August 2009, Columbia, MO (basket courtesy of Marcia Beck).

The 2010 Longaberger Horizon of Hope Basket.
Industry Partnerships

On behalf of the American Lymphedema Framework Project team, our executive and steering committees, and all our existing stakeholders, we are deeply grateful for the support received from our industry partnerships. These supporters are not just financial sponsors, but partners in helping the ALFP to move toward achieving the mission to improve the awareness and management of lymphedema in the U.S.

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