THE CASE FOR LYMPHEDEMA LEGISLATION
An Open Letter to my Congressional Representatives

One of the major policy challenges facing Medicare is "strengthening protections for low-income, chronically ill, and otherwise vulnerable beneficiaries" (1). It is further pointed out that the Medicare population will grow by 85% in the next 25 years, growing from 42.7 million to 79.0 million by 2030 (2). The problem is further compounded for cancer survivors. "Cancer survivors have poorer health outcomes than do similar individuals without cancer across multiple burden measures. These decrements are consistent across tumor sites and are found in patients many years following reported diagnosis"(3). Economic losses are not limited to healthcare providers. The indirect economic effects of long-term breast cancer survival were studied by Chirikos et. al. (4) with the conclusion "Clinicians and policy makers must seek ways to minimize the indirect economic losses attributable to breast cancer."

What is proposed here is a piece of "smart legislation" which will target a growing segment of the Medicare population and provide improved access to effective, conservative, proven treatment while saving precious Medicare money and minimizing patient economic burden. We are asking you to help us achieve this goal by sponsoring our Lymphedema Treatment Cost Saving Bill of 2007.

The estimated number of cancer survivors alive in 2005 is 10,454,000 by American Cancer Society projections. Best estimates found in medical literature of the incidence of lymphedema caused by cancer treatment is approximately 20%, (5) meaning that there will be an estimated 2 million cancer survivors who would benefit from lymphedema treatment. Sixty one percent of cancer survivors in 2005 are over 65 years of age (NCI estimate), meaning that as many as 1.25 million Medicare beneficiaries who are cancer survivors will require treatment for their lymphedema in 2005. To this burden is added a percentage of survivors of various surgical and radiative procedures such as coronary artery bypass, hip and knee replacement, head and neck surgery, survivors of repeated cellulitis and lymphangitis episodes and patients with primary lymphedema.

Unfortunately, U.S. physicians and health care personnel are woefully unaware of the extent of this condition, and the protocols of its medical treatment. **Medicare and other health care insurers rarely cover the medical protocols practiced in Europe for over fifty years (6), and recommended in the U.S. in 1998 (7). The sad part of all of this is that the majority of patients suffer their swollen limbs in silence, being told by their physicians that there is nothing to be done, and that they are lucky to be alive.** American doctors have not been schooled in the lymphatic system and its pathologies, and are for the most part unaware of the treatments that have been used in Europe for the last 50 years. And many of these patients are now on disability and bedridden with a condition that is treatable but not being treated. (Reference patient "Joell" from the San Francisco Bay area featured last February on the Dr. Phil show, who was not being treated for her lymphedema until we brought it to the medical staff's attention.)

This under-diagnosing and under-treating of lymphedema patients costs healthcare providers and healthcare insurers including Medicare untold millions of dollars every year because the untreated lymphedematous limb is greatly at risk for infection (cellulitis and lymphangitis) which comes on in the course of a few hours and requires immediate treatment on an emergency basis. It has been shown that treatment of lymphedema greatly reduces and eliminates the risk of infection. (8,9)

With the current attention in Congress on implementing the Medicare Prescription Drug,

Improvement, and Modernization Act of 2003 and other sweeping changes to Medicare, attention has been diverted from inequities and inefficiencies in coverage for individual beneficiary subgroups. One of these Medicare subgroups comprises the 1.25 to 2 million lymphedema sufferers. Broad sweeping changes to save Medicare are necessary, but we are being shortsighted if we do not simultaneously **make incremental changes to improve the quality of medical care—*especially if these improvements will save money*.**

Current Medicare policy covers some, but not all of the complex decongestive therapy (CDT) protocols recommended for the medical treatment of lymphedema. The partially covered protocol is manual lymph drainage (MLD) used in the treatment of lymphedema performed by a physical therapist in an outpatient setting. Medicare also provides pneumatic pumps, which are not recommended as a primary treatment modality, but are recognized as an adjunct to the primary CDT. The catch is that the primary recommended therapy for lymphedema includes adequate manual lymph drainage, bandaging, the wearing of compression garments, exercising while wearing compression, and skin care. Medicare does not provide compression bandages or compression garments, and they limit, through the Congressionally imposed therapy cap, the amount of manual lymph drainage. Without coverage of the recommended treatment of lymphedema, it is very difficult to assure patient compliance, and it almost guarantees failure of the therapy, leading to frequent infections requiring emergency treatment. And this failure of the therapy ironically makes the patient eligible for the pneumatic pump that is contraindicated without accompanying manual lymph drainage and compression therapy.

This is not a new health care mandate that needs new funding. Rather, it is a protocol that can utilize in-place medical personnel, equipment and facilities, and has been shown to be at least cost-neutral, and at best can save Medicare and our healthcare providers hundreds of millions of dollars in unnecessary treatment of avoidable infections, avoidable pain and avoidable disability and deformity.

The proposed bill is structured as a set of additions to relevant sections of Title XVIII of the Social Security Act, which establishes and governs Medicare**. It would provide Medicare coverage for diagnosis and treatment of lymphedema from any cause, impose quality requirements on any person who treats lymphedema under the law, define the standard of treatment for lymphedema, provide bandages, garments and devices for the treatment of lymphedema, provide treatment frequency, duration and number as determined by medical necessity, provide for quality standards for garment fitters, etc.**

The General Assembly of Virginia has recently passed legislation for lymphedema treatment (VA H.B. 1737 Wardrup) which was deemed to have **no fiscal or budgetary impact** by the Virginia Department of Corporations (10). This Virginia lymphedema treatment law took effect January 1, 2004. The Massachusetts Senate and House are considering bills (MA S 848/2471 Fargo and H.B. 1309 Walsh) which will provide coverage for lymphedema treatment. Similar bills are being considered in New York State (NY A 9208A/A 5003 Cohen and S 7005 Fuschillo), in California (AB-213 Liu) and in Connecticut (SB 119 Harp).

The Massachusetts mandate analysis done by Compass Health Analytics (11) resulted in a mid-range per member per month (PMPM) cost of the proposed mandate of $.0268 PMPM for 2005, which would gradually increase to $.0304 by 2009. This analysis did not account for the expected savings resulting from the improved quality of lymphedema treatment, reduced infection rate or reduced disability.

A preliminary cost-efficacy model has been presented by Robert Weiss which demonstrates, by

means of an analytical model populated with medical journal-published statistics, the anticipated savings if lymphedema is treated by current medically-recommended protocols (12). **Health care costs to treat the hypothetical breast cancer survivor are 3.5 times more when her lymphedema is not treated.**

Please understand that this is NOT a new health mandate. The staff, equipment and facilities are already in place in most medical providers. Most providers and insurers already claim to treat lymphedema, and there are no exclusions in any medical policies that we are aware of. **The Women's Health and Cancer Rights Act of 1998 already mandates the treatment of lymphedema resulting from breast cancer treatment.**

We look forward to working with you on a bill to **save Medicare millions of dollars in health care costs** while assuring a greatly **improved quality of life for thousands of its beneficiaries.**

(1) Tricia Neuman, Sc.D. Vice President and Director, Medicare Policy Project, The Henry J. Kaiser Family Foundation "Medicare 101" January 2005.
(2) CMS Office of the Actuary, January 2003.
(3) Yabroff KR, Lawrence WF, Clauser S, Davis WW & Brown ML: "Burden of Illness in Cancer Survivors: Findings From a Population-Based National Sample" *J Natl Cancer Inst* 2004;96:1322–30.
(4) Chirikos TN, Russell-Jacobs A & Cantor AB: "Indirect Economic Effects of Long-Term Breast Cancer Survival" *Cancer Practice*, Sept. 2002;10(5):248.
(5) Weiss R: "Incidence of lymphedema: a literature review" plenary session presentation at the 6th International NLN Conference "New Frontiers in Lymphedema Research and Therapy", Reno, NV October 2004. (to be published in *Lymphology*)
(6) International Society of Lymphology, Executive Committee: "The Diagnosis and Treatment of Peripheral Lymphedema, Consensus Document", *Lymphology*, 2003;36:84-91.
(7) Rockson SG, Miller LT, Senie R, Brennan MJ, Casley-Smith JR, Földi E, Földi M, Gamble GL, Kasseroller RG, Leduc A, Lerner R, Mortimer P, Norman SA, Plotkin CL, Rinehart-Ayres ME & Walder AL: "Workgroup III: Diagnosis and Management of Lymphedema" *Cancer*, Dec 15, 1998;83(12 Supplement):2882-5, American Cancer Society Workshop on Breast Cancer Treatment-Related Lymphedema, New York, NY, February 20-22, 1997.
(8) Földi, E: "Prevention of Dermatolymphangioadenitis by Combined Physiotherapy of the Swollen Arm after Treatment of Breast Cancer", *Lymphology* 1996;29:91-4.
(9) Ko DSC, Lerner R, Klose G & Cosimi AB: "Effective Treatment of Lymphedema of the Extremities" *Arch of Surg* April 1998;133:452-8.
(10) State Corporation Commission, "2003 Fiscal Impact Statement—Bill Number HB1737" March 4, 2003.
(11) Commonwealth of Massachusetts, Mandated Benefit Review "Review and Evaluation of Proposed Legislation Entitled: 'An Act Providing Coverage for Lymphedema Treatments' Companion bills: Senate Bill No. 848 & House Bill No. 1309" Provided for: The Joint Committee on Insurance, Division of Health Care Finance and Policy, Commonwealth of Massachusetts, July 26, 2004.
(12) Weiss R: "A Cost-Efficacy Model for Treatment of Lymphedema" a workshop given at The First Montreal International Lymphedema Congress "Lymphedema: A Health Care Problem" Wyndham Hotel, Montreal, Quebec May 28- 30, 2003.