



Physical & Occupational Therapy Services
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Dr. Francis Collins
Director
National Institutes of Health
Francis.Collins@nih.hhs.gov

Dr. James Madara
CEO and Executive Vice President
American Medical Association
james.madara@ama-assn.org

Dear Drs. Collins and Madara,

I am writing to you as the Associate Director of the Lymphedema Research Program at the Massachusetts General Hospital (MGH), a American Physical Therapy Association Board-Certified Physical Therapy Clinical Specialist within the MGH Physical and Occupational Therapy Department and a Certified Lymphedema Therapist. The focal point of my work concerns the minimization of treatment-related side effects including lymphedema, shoulder and chest wall morbidity and fatigue/deconditioning to improve the quality of life for patients who have undergone treatment for breast cancer. My current and future research protocols focus on survivorship and investigation of symptoms, impact on quality of life and early detection and intervention of breast cancer-related lymphedema. I have been part of the Lymphedema Research Program at the Massachusetts General Hospital since 2013. I have treated patients with lymphedema for more than 20 years. This team pioneered the implementation of and sustained a successful prospective surveillance (screening) model for breast cancer related lymphedema (BCRL) since 2005 through which over 5,500 patients have been screened. It is with this experience that I urge your support for the FY2022 appropriations bill which directs the NIH to establish a National Commission on Lymphatic Diseases and specifically a research category for lymphedema.

BCRL remains one of the most feared complications among breast cancer survivors due to the significant negative impact on quality of life (QOL). While one in five women treated for breast cancer develop BCRL, the risk of development persists for a lifetime. Late-stage lymphedema is an irreversible condition that carries a large emotional and economic burden for the patient and strains the finite treatment resources for these patients. Through our screening program, we are able to identify patients at the early stages of lymphedema, when treatment has its best chance of success. Our goal with the lymphedema research program has been to change the management of lymphedema from an impairment-based model to a prospective screening-based model. However, there is much work to do in order to establish universal diagnostic criteria, better define the role of symptoms in diagnosis, establish a universal threshold for treatment and to establish best treatment parameters to ensure success of care for patients suffering from lymphedema.

I often hear from my patients that lymphedema has been worse than a cancer recurrence for them. Lymphedema treatment is burdensome and its course is unpredictable. It is a visual reminder of breast cancer for patients who are trying to move on from cancer treatment, affecting their daily function, their ability to interact with their loved ones, even their sleep, and has a major impact on their quality of life. One of my patients, who lived with metastatic breast cancer for more than 10 years, developed lymphedema in her legs as a consequence of her metastases. She was incredibly ill with breast cancer, however, it was her lymphedema that was the worst part of her illness. After she died, her husband stated *"Lymphedema became a part of our lives as it strangled the mobility and quality of life from [my wife] and consequently from me. ... it eventually took over and was the worst part of [my wife's] illness"*.



MASSACHUSETTS
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The establishment of a National Commission on Lymphatic Diseases and a specific research category for lymphedema allows for the commitment of additional resources and highlights the importance of addressing a life-altering condition that has been understudied and under-supported. This is an opportunity to discover innovative solutions that reduce the risk of lymphedema, control its progression and establish universal diagnosis and treatment guidelines.

I urge you to support the FY2022 appropriations bill directing the NIH to establish a National Commission on Lymphatic Diseases and a research category for lymphedema. If you or your staff would like additional information on the FY2022 appropriations bill, please contact me directly. I look forward to keeping you informed about our progress and working with your office in the future.

Sincerely,

Cheryl Brunelle, PT, MS, CCS, CLT
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