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Dear Drs. Collins and Madara,

I am writing to you as the Director of the Lymphedema Research Program at the Massachusetts General Hospital (MGH), a Breast Radiation Oncologist within the MGH Cancer Center, and an active Professor at Harvard Medical School. The focal point of my work concerns the minimization of treatment related side effects and complications to improve the quality of life for patients while not compromising the expected benefit of the cancer therapy. 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. In 2005, I founded the Lymphedema Research Program at the Massachusetts General Hospital and have since pioneered the implementation of and sustained a successful prospective surveillance (screening) model for breast cancer related lymphedema (BCRL) 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 considered to be an irreversible condition that also carries a tremendous impact on the patient's quality of life. Those are quotes from a study we conducted in 2017: "*…lymphedema almost immediately after surgery, …. It has ruined my life. I feel like a freak. I'd almost rather I had died", "I fear lymphedema more than recurrence", "Lymphedema was almost worse than having my breasts removed. I was bitter, I was depressed. I thought my career was over, I thought, 'There's no way, I'm done, everything is done", "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".*

Furthermore, lymphedema has shown to have a significant economic burden for the patient and the health care system. Our goal with the lymphedema research program was to change the management of lymphedema from an "Impairment-based model" into a "Screening-based model". 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 overlooked for far too long. This is an opportunity to make a difference in the lives of all individuals with lymphatic diseases as well as a chance to discover innovative solutions that reduce the risk of lymphedema and make the condition

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,

A. Taghian

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