



June 27, 2019

BOARD OF DIRECTORS

Mark Dant, Board Chair

Executive Director
Ryan Foundation

Frank J. Sasinowski, Board Vice Chair

Director, Hyman, Phelps &
McNamara, P.C.

Vicki Seyfert-Margolis, PhD,

Treasurer
Founder and CEO, MyOwnMed

Julia Jenkins, Secretary

Executive Director
EveryLife Foundation

Emil D. Kakkis, MD, PhD

Founder
President/CEO, Ultragenyx

Ritu Baral

Managing Director & Senior
Biotechnology Analyst
Cowen and Company

Jennifer Bernstein

Executive Vice President, Horizon
Government Affairs

Amrit Ray MD, MBA

Global President, Research,
Development & Medical
Upjohn Pfizer, Inc.

*The EveryLife Foundation for
Rare Diseases is a 501(c)3 organization
Tax ID # 26-4614274*

**1012 14th Street, NW
Washington, DC 20005
(202) 697-RARE (7273)
www.everylifefoundation.org**

Honorable Maria Cantwell
U.S. Senate
511 Hart Senate Office Building
Washington, DC 20510

Honorable Todd Young
U.S. Senate
400 Russell Senate Office Building
Washington, DC 20510

Dear Senators Cantwell and Young:

On behalf of the EveryLife Foundation for Rare Diseases, thank you for your leadership in introducing S. 518, the Lymphedema Treatment Act. The EveryLife Foundation is a nonprofit dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-based public policy.

We strongly support the Lymphedema Treatment Act which would provide a Medicare benefit category for coverage of the physician-prescribed compression supplies used in the treatment and management of lymphedema.

Lymphedema is chronic swelling (edema) caused by a build-up of fluid (lymph) that occurs when the lymphatic system is either faulty or damaged and is associated with over 40 rare diseases. There is no cure for lymphedema, but it can be effectively treated.

Compression is to lymphedema as insulin is to diabetes. Compression treats the disease and prevents complication, enabling patients to remain healthy and productive while reducing overall healthcare expense.

Currently, Medicare does not cover these critically necessary compression supplies as they are not classified under any existing Medicare benefits category.

Without compression garments, the disease progresses, often resulting in hospitalization for life-threatening cellulitis infections. Compression stockings are the most effective and least expensive treatment to control the disease and can save overall health care dollars.

Thank you for supporting the Lymphedema Treatment act which would help prevent the needless suffering of millions of Americans who have lymphedema, improve the quality of their lives and reduce overall healthcare costs.

Sincerely,

Julia Jenkins
Executive Director