

LYMPHEDEMA: NOT ONE DISEASE

Chronic lymphatic-system failure (lymphedema) occurs in 3-5 million Americans across a wide spectrum of diseases.



10% of all cases are **Primary** (congenital)^{1,3,6-7}

Over 40 rare diseases are associated with primary lymphedema including:

- Aagenaes Syndrome
- Adams-Oliver Syndrome
- C.H.A.R.G.E. Syndrome
- C.L.O.V.E.S. Syndrome
- Carbohydrate Deficient Glycoprotein (types 1a, 1b, 1h)
- ardio-facial-cutaneous Syndrome
- Choanalatresia-lymphedema Syndrome
- Congenital Lymphedema (non-Milroy's)
- Ectodermal Dysplasia Anhidrotic
- Immunodeficiency Osteopetrosis
- Lymphedema Syndrome
- Fabray's Disease
- Gorham's Disease
- Hennekam Syndrome
- Hypotrichosis Lymphedema Telangiectasia
- Klippel Trenaunay Syndrome
- Klippel-Trenaunay-Weber Syndrome
- Lipedema
- Lymphedema Distichiasis Syndrome
- Lymphedema Myelodysplasia (Emberger Syndrome)
- Lymphedema Praecox
- Lymphedema Tarda
- Lymphedema-Distichiasis
- Macrocephaly-Capillary Malformation
- Maffucci Syndrome
- Meige Syndrome
- Microcephaly-Chorioretinopathy-Lymphedema-Mental Retardation Syndrome
- Milroy's Disease
- Mucke Syndrome
- Neurofibromatosis
- Nonne-Milroy Disease
- Noonan's Syndrome
- Oculo-Dento-Digital Syndrome
- Parkes-Weber Syndrome
- Phelan McDermid Syndrome
- Prader Willi Syndrome
- Progressive Encephalopathy-Hypsar-rhythmia-Optic Atrophy Syndrome
- Protein Losing Enteropathy (associated with numerous forms of congenital heart disease)
- Proteus Syndrome
- Spina bifida
- Thrombocytopenia with Absent Radius Syndrome
- Trisomy 13,18,21
- Turner's Syndrome
- Velocardiofacial Syndrome
- W.I.L.D. Syndrome

90% of all cases are **Secondary** (acquired)^{1,2,4,5}

Secondary cases can be broken into two categories:

22% of all cases are **non-cancer** related. Any significant damage to the lymphatic organ system can result in lymphedema. Causes include:

- Burns
- Ilio-femoral bypass
- Infection
- Paralysis
- Radiation
- Rheumatoid arthritis
- Surgery
- Trauma

68% of all cases are **cancer** related. The overall cancer-related incidence rate is 15.5%. Specific rates include:

- Breast 40%
- Sarcoma 30%
- Gynecological 20%
- Melanoma 16%
- Genital-urinary 10%
- Head and neck 4%

1. *Journal of the American College of Cardiology*. 2008; 52 (10): 799-806
2. *Vascular Medicine*. 1998; (3): 145-156
3. *Clinical Genetics*. 2010; 77: 438-452
4. *Cancer*. 2010; 116: 5138-49
5. *Journal of Clinical Oncology*. 2009; 27:(3): 390-7
6. *Annals of the New York Academy of Sciences*. 2008; 1131: 147-154
7. *European Journal of Cancer Care*. (Engl.) 1996; 5: 56-59



For more information visit our website
LymphedemaTreatmentAct.org



the Making Case

for S.518 / H.R.1948

COVID-19 UPDATE

Summer 2020


Prioritizing Preventative Care


5 Reasons Why Passage of the **Lymphedema Treatment Act** is Vital during the COVID-19 Pandemic



1 The lymphatic system is an integral part of the immune system. Patients with lymphedema (chronic lymphatic system failure) are at even higher risk when their condition is not managed properly.¹

2 This legislation will prevent avoidable hospitalizations, doctor and therapy visits,² and help at-risk seniors stay healthy at home.

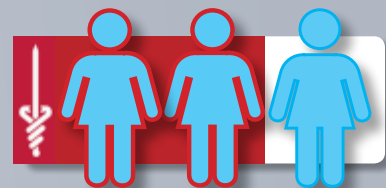
40% drop in visits to physicians and therapists 

50% drop in days spent in the hospital 

3 At least 3 million Americans have lymphedema, with half being Medicare beneficiaries.³



4 Two-thirds of all lymphedema patients are cancer survivors,⁴ some currently receiving cancer treatment.



5 Overwhelming bipartisan support, making it the most supported healthcare bill in Congress.

House Cosponsors	382	
Senate Cosponsors	70	
Total	452	

Click to see list of [House](#) and [Senate](#) cosponsors.

¹ <https://tinyurl.com/yx7ff7c5>

² <https://tinyurl.com/u9kznm4>

³ <https://tinyurl.com/vnos42e>

⁴ <https://tinyurl.com/rjx6xph>