LYMPHEDEMA: NOT ONE DISEASE

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

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)
- cardio-facial-cutaneous Syndrome
- Choanalatresia-lymphedema Syndrome
- Congenital Lymphedema (non-Milroy’s)
- Ectodermal Dysplasia Anhidrotic Immunodeficiency Osteopetrosis
- Lymphedema Syndrome
- Fabry’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
- Muckle Syndrome
- Neurofibromatosis
- Nonne-Milroy Disease
- Noonan’s Syndrome
- Oculo-Dento-Digital Syndrome
- Parkes-Weber Syndrome
- Phelan McDermid Syndrome
- Prader Willi Syndrome
- Progressive Encephalopathy-Hypsarhythmia-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

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%

For more information visit our website LymphedemaTreatmentAct.org

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.

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. Click to see list of House and Senate cosponsors.