

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)
- 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
- Mucke Syndrome
- Neurofibromatosis
- Nonne-Milroy Disease
- Noonan's Syndrome
- Oculo-Dento-Digital Syndrome
- Parkes-Weber Syndrome
- Phelan McDerimid 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
- Yellow Nail 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



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Education & Awareness
PROJECT



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For more information visit our websites:

LymphedemaProject.org

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