

Lymphedema: Not One Disease

Chronic lymphatic-system failure (lymphedema) occurs across a wide spectrum of diseases.



Primary

Secondary

10% of all cases are Primary (congenital)^{1,3,6,7}
(persons shown in red)

90% of all cases are Secondary (acquired)^{1,2,4,5}
(persons shown in blue and green)

Over 40 rare disease are associated with primary lymphedema including:

- Aagaenae 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
- 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-Hypsarrhythmia-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

22% of all cases are non-cancer related

Any significant damage to the lymphatic organ system can result in lymphedema

Causes include:

- burns
- radiation
- Ilio-femoral bypass
- rheumatoid arthritis
- infection
- surgery
- paralysis
- trauma

68% of all cases are cancer-related

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%

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LymphedemaTreatmentAct.org