



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Orthopaedic

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- Orthopaedic involvement may be needed for evaluation of joint contractures (especially elbows), hip problems, leg length discrepancy, bunions and Achilles tendon tightness
- Most orthopaedic manifestations do not require surgery
- Physical therapy is the main treatment for most musculoskeletal problems in CdLS
- Back should be examined and monitored for scoliosis
- As an adult, consider a DEXA scan to rule out early onset osteoporosis
- It is important that individuals with CdLS be evaluated and followed at some regular interval for gastroesophageal reflux (GER). Unexplained pain/discomfort or acting out may be due to an underlying medical condition. Management and treatment guidelines are available www.cdlsusa.org.
- Ensure that the family has the CdLS Medical Alert Card, available from the CdLS Foundation Web site, which would be helpful in an emergency situation (e.g. risk for volvulus).

Support organization information should be given to the family whenever a diagnosis is made:

The CdLS Foundation

1-800-753-2357

www.CdLSusa.org.