



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Cardiology

- An individual with CdLS should have regular evaluations and immunizations with the primary care provider.
- Echocardiogram at time of diagnosis.
- Follow up with appropriate subspecialists as needed.
- Whenever any surgery is performed, all involved specialists should be consulted in order to maximize the use of anesthesia and so that the individual can undergo diagnostic or management studies as needed at the same time.
- 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.