



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

REACHING OUT. PROVIDING HELP. GIVING HOPE.

Behavior

- Autistic-like symptoms and autism may be present.
- Behavioral assessment if issues arise, including ADHD, self-injurious behavior, aggression.
- Be aware that individuals with CdLS may develop anxiety and depression.
- Self-injurious behavior may be related to an untreated medical condition, the most common being gastric reflux. The frequency with which unsuspected reflux has proven the basis for behavioral change has led us to strongly recommend that every person with the diagnosis of CdLS be given an evaluation for gastroesophageal reflux disease (GERD) which may include pH probe/impedance study, nuclear medicine scan and/or endoscopy.
- 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.