CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

CdLS / CdLS Foundation Talking Points

- **CdLS** stands for **Cornelia de Lange Syndrome.** (Pronounced: deh lahng/long)
- The exact incidence of CdLS is not confirmed, but it is thought to be approximately 1 in 10,000 live births.
- An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services.
- Characteristics - Individuals with CdLS range from mildly to severely affected, though most have similar physical characteristics including small size, hands and feet; thin eyebrows that meet in the middle; long eyelashes; an upturned nose; and thin, downturned lips. Some individuals have limb differences (around 25%), including missing fingers or arms.
- **Common medical problems include** Gastroesophageal Reflux Disease (GERD), bowel obstruction, hearing loss, and congenital heart defects. Other characteristics include low birth weight (often under five pounds), slow growth, small stature, and small head size. Behavioral and communication issues and developmental delays often exist.
- Early diagnosis and intervention is essential to ensure proper management of related medical issues.

The CdLS Foundation

- The Cornelia de Lange Syndrome Foundation is a national nonprofit family support organization that exists to ensure early and accurate diagnosis of CdLS, promote research into the causes and manifestations of the syndrome, and help people with a diagnosis of CdLS and their families make informed decisions throughout their lifetime.
- The CdLS Foundation serves about 2,700 people with CdLS in the U.S., along with about 10,000 parents and relatives, and thousands of professionals.
- The CdLS Foundation is the only organization solely dedicated to CdLS in the country.
- The CdLS Foundation has served people with CdLS and their families since 1981.
- **Web site -** www.CdLSusa.org **Toll-free Phone-** 800-753-2357