



## Cornelia de Lange Syndrome Foundation, Inc.

302 West Main Street, #100  
Avon, CT 06001-3681

Phone: 860.676.8166  
Toll free: 800.223.8355  
fax: 860.676.8337  
[www.CdLSUSA.org](http://www.CdLSUSA.org)

---

### Cornelia de Lange Syndrome Foundation Timeline & Milestones

- 1933** Dutch physician Dr. Cornelia de Lange identifies two children with similar features and describes the set of symptoms that comprise the syndrome.
- 1970** Realizing the importance of sharing information, Sue Anthony and Carol Welsh meet in a Seattle airport with their children, who have CdLS.
- 1977** Anthony and Welsh create the first issue of *Reaching Out*, a bi-monthly newsletter geared toward parents of children with CdLS. It is sent to nine people.
- Anthony sends a list of questions to geneticist Dr. Laird Jackson. He replies and begins a long-time relationship with people who have CdLS and their families.
- 1978** *Reaching Out* is sent to 30 people.
- 1979** A directory featuring 23 children with CdLS is printed.
- 1980** The first gathering of CdLS families takes place in Maryland.
- 1981** The CdLS Foundation is incorporated. The office and its one paid staff person are based in the kitchen of a construction company office.
- 1982** *Reaching Out* is mailed to 400 people. The first CdLS fact sheets are created.
- 1983** Dr. Jackson is named the Foundation's first medical director.
- 1984** *Reaching Out* is sent to 1,000 people.
- 1985** The first CdLS conference is held in Indianapolis. It is held there again the following year.
- 1987** The first CdLS Clinic Day and third conference are held in Philadelphia.
- 1988** The Foundation purchases its first computer. It joins an existing inventory of two answering machines, one typewriter, three chairs, and one desk.
- The Regional Coordinator program is formalized, using volunteer parents across the country to offer support to fellow CdLS families.
- 1989** The first National CdLS Awareness Day is observed.
- 1990** Dr. Jackson begins formal collection of blood samples for CdLS research.
- The Foundation hires its first Family Service Coordinator.
- 1991** A CdLS Scientific Advisory Board (SAC) is established. It has 11 members.

- 1992** Dr. Antonie Kline develops the first CdLS growth and development charts.
- 1993** CdLS is featured in the *American Journal of American Genetics*.
- 1995** *Reaching Out's* mailing list reaches 3,800.  
There are 75 Regional Coordinators.
- 1996** The Foundation launches a web site.
- 1997** The Awareness Coordinator program begins with 33 volunteers charged with raising awareness of CdLS in their communities.  
The Foundation moves into its first non-donated office space.
- 1998** The Ask the Doctor feature is added to the CdLS web site.
- 1999** A second Family Service Coordinator is added to staff.
- 2000** Dr. Kline becomes the Foundation Medical Director.
- 2001** The first CdLS Clinic for Adolescents is organized by Dr. Kline at the Greater Baltimore Medical Center.
- 2002** The National Institutes of Health awards Dr. Ian Krantz of the Children's Hospital of Philadelphia (CHOP) a grant to study CdLS.  
*Reaching Out* marks 25 years of continuous bi-monthly publication.
- 2003** CdLS World Federation is established.
- 2004** Dr. Krantz and his research team identify the genetic mutation that causes CdLS—*NIPBL* on Chromosome 5.  
A CdLS Clinical Advisory Board is established in the US as a subset of the International SAC.
- 2005** The Foundation awards five research grants totaling \$25,000.
- 2006** An Italian team of researchers identifies a second genetic mutation that leads to CdLS—*SMC1A* on the X Chromosome.  
The Foundation celebrates its 25<sup>th</sup> Anniversary. The 23<sup>rd</sup> National Conference is held in Cherry Hill, NJ.
- 2007** A third gene is discovered by researchers at CHOP. This gene—*SMC3* on Chromosome 10—seems to correlate with a milder form of CdLS.  
*Reaching Out* marks its 30<sup>th</sup> year.
- 2008** Julie Mairano, the Foundation's co-founder and its first and only executive director, retires. Liana Garcia-Fresher takes over the position.  
The 24<sup>th</sup> national CdLS Foundation conference is June 26-29 in Chicago.