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### **Foundation awards handed out during conference**

**Avon, CT (July 8, 2010)** - The Cornelia de Lange Syndrome (CdLS) Foundation recently awarded volunteers for their commitment to individuals with CdLS and to the Foundation.

Liana Fresher, executive director of the Foundation and David Fowler, board president of the Foundation, presented the awards June 26 at the Foundation's biennial banquet in Dallas, TX. The following awards were handed out:

Tim Tietgens of Leominster, MA, received the Mark Etcheberry Award, which is given to an individual who has dedicated his or her efforts and talent to increase awareness of CdLS and the Foundation. Tietgens is a long-time awareness coordinator in Massachusetts. He has presented information about CdLS throughout his community and is a role model for all people with CdLS.

The John King Award was presented to three individuals, whose long-term efforts on behalf of the Foundation have made a notable impact. The award was given to three people this year: Frank Mairano of Collinsville, CT, Linda Berger of Avon, CT, and Maureen Schuler of Roscoe, IL. They were recognized for their dedication to running the conference doctor consultations for decades.

Kari Cunningham-Rosvik of Seattle, WA, received the Sue Anthony Award, which is given to a person who has developed a creative approach to improve the quality of the Foundation and its ability to fulfill its mission. Cunningham-Rosvik is a long-time volunteer serving as a regional coordinator, board member and head of the Foundation's program council.

Dr. Dale Dorsett of St. Louis, MO, received the Doctor Laird Jackson Award, which honors an individual's medical or scientific contributions toward understanding CdLS and improving the lives of people affected by the syndrome. Dr. Dorsett's work with fruit flies has led to increased knowledge about why and how CdLS happens.

The President's Award was given to two women this year: Joanne Gersuk of Plano, TX, and Dr. Elizabeth Gersuk of Carrboro, NC. This mother-daughter team volunteers at every conference, running the registration desk and helping out wherever needed.

Special recognition awards were presented to the University of Chicago Genetic Services Laboratories and to Dr. Carol Potter of Columbus, OH. The University of Chicago Genetic Services Laboratories sponsored the banquet and Dr. Potter has been answering families' questions about gastrointestinal issues for more than a decade.

### **About CdLS**

CdLS is a genetic syndrome that occurs in about 1 in 10,000 births. An estimated 20,000 people in the U.S. have CdLS but remain undiagnosed and/or without support services. Although individuals with CdLS range from mildly to severely affected, most have similar physical characteristics: small size, hands and feet; thin eyebrows that meet in the middle; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms, and partial joining of the toes. Common medical problems include gastroesophageal reflux, bowel obstruction, hearing loss, and congenital heart defects.

### **About the Foundation**

Founded in 1981, the Cornelia de Lange Syndrome Foundation is a 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 make informed decisions throughout their lifetime. For more information, call 800-753-2357 or go to [www.cdlsusa.org](http://www.cdlsusa.org).

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