



CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.
Reaching Out, Providing Help, Giving Hope

Contact: Marie Concklin Malloy, Director of External Affairs
outreach@CdLSusa.org; 800-753-2357

Funding aids CdLS research, outreach

AVON, CT (April 2, 2009)—Cornelia de Lange Syndrome (CdLS) research and awareness efforts are both getting a boost from the federal government.

Dale Dorsett, Ph.D., whose research with fruit flies aided in the discovery of one of the gene mutations responsible for CdLS, received renewed funding of \$217,500 per year through 2012 from the National Institute of General Medical Sciences.

Dr. Dorsett's work with fruit flies increases understanding of the molecular mechanisms that cause CdLS, which could make it easier in the future to develop new diagnostic and therapeutic methods for CdLS.

Dr. Dorsett, who chairs the Foundation's Research Council and sits on the Clinical Advisory Board, is based at St. Louis University School of Medicine.

Additionally, the CdLS Foundation has received a commitment of \$238,000 in one-time federal funding from the Centers for Disease Control for educational and outreach services.

This funding will enable the Foundation to provide support and information to families of children with CdLS, as well as raise awareness of the syndrome and the life-changing benefits of diagnosis.

"The funding allows the Foundation to enhance its current services and increase its outreach effort to the public, educators and health care professionals, many whom have never heard of CdLS," said Executive Director Liana Fresher.

The \$238,000 in funding to the Foundation was made possible with support from Connecticut Senators Christopher Dodd and Joseph Lieberman.

What is 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; arched eyebrows that meet in the middle; long eyelashes; upturned nose; and thin, downturned lips. Some individuals have limb differences, including missing fingers or arms, partial joining of the toes, and limitation of elbow extension. Common medical problems include gastroesophageal reflux, bowel malrotation, hearing loss, and congenital heart defects.

About the Foundation

Founded in 1981, the Cornelia de Lange Syndrome (CdLS) 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.

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