

Senate Resolution 135

By: Senators Butler of the 55th, Seay of the 34th, James of the 35th, Sims of the 12th, Unterman of the 45th and others

A RESOLUTION

1 Recognizing May 11, 2013, as Cornelia de Lange Syndrome Awareness Day; and for other
2 purposes.

3 WHEREAS, Cornelia de Lange Syndrome (CdLS) is a congenital syndrome that causes a
4 range of physical, cognitive, and developmental disabilities, and occurs in approximately one
5 in 10,000 live births; and

6 WHEREAS, the effects of CdLS range from mild to severe, affecting all races and ethnic
7 backgrounds; and

8 WHEREAS, signs and symptoms of CdLS are low birth weight, slow growth, small stature,
9 and small head size; and behavioral, communication, and cognitive challenges often exist;
10 and

11 WHEREAS, an estimated 20,000 men, women, and children in the United States have CdLS
12 but remain undiagnosed or without support services, missing out on critical medical services
13 and support that can impact their quality of life; and

14 WHEREAS, the CdLS Foundation was founded in 1981 by parents of children with CdLS
15 and is the only organization in the country devoted to the syndrome, serving more than 2,400
16 people with CdLS, 10,000 family members and caregivers, and 2,500 professionals; and

17 WHEREAS, the organization exists to ensure early and accurate diagnosis of CdLS; to
18 promote research into the causes and manifestations of the syndrome; and to help people with
19 a diagnosis of CdLS make informed decisions throughout their lives; and

20 WHEREAS, dedicated professionals are involved in valuable research to explore new
21 therapies and diagnostic tools and to offer hope to children with CdLS.

22 NOW, THEREFORE, BE IT RESOLVED BY THE SENATE that the members of this body
23 recognize May 11, 2013, as Cornelia de Lange Syndrome Awareness Day and commend
24 efforts to help individuals with this syndrome.

25 BE IT FURTHER RESOLVED that the Secretary of the Senate is authorized and directed
26 to transmit an appropriate copy of this resolution to the Cornelia de Lange Foundation.