

1 A RESOLUTION declaring the second Saturday in May each year as Cornelia de
2 Lange Syndrome Awareness Day in the Commonwealth.

3 WHEREAS, Cornelia de Lange Syndrome (CdLS) is a very rare genetic disorder
4 that is apparent at birth; and

5 WHEREAS, CdLS is characterized by growth delays, distinctive facial features,
6 malformations of the hands, feet, arms, or legs, other physical abnormalities, intellectual
7 disabilities, and developmental delays; and

8 WHEREAS, CdLS occurs in approximately one in every 10,000 live births in the
9 United States; and

10 WHEREAS, more than 400 cases have been reported in medical literature,
11 including affected individuals within several related families;

12 NOW, THEREFORE,

13 *Be it resolved by the House of Representatives of the General Assembly of the*
14 *Commonwealth of Kentucky:*

15 ➔Section 1. The House of Representatives hereby declares the second Saturday in
16 May each year as Cornelia de Lange Syndrome Awareness Day in the Commonwealth.

17 ➔Section 2. The House of Representatives finds that it is in the interest of the
18 Commonwealth to increase public awareness of Cornelia de Lange Syndrome, a very rare
19 genetic disorder. Early intervention is important in ensuring that children with CdLS
20 reach their highest potential. Services that may be beneficial include special remedial
21 education, vocational training, speech therapy, and other medical and social services.
22 Genetic counseling is recommended for affected individuals and their families and other
23 treatment is symptomatic and supportive.