

Introduced by Senator Beall

April 18, 2016

Senate Concurrent Resolution No. 133—Relative to Gastroschisis Awareness Day.

LEGISLATIVE COUNSEL’S DIGEST

SCR 133, as introduced, Beall. Gastroschisis Awareness Day.

This measure would recognize July 30, 2016, as Gastroschisis Awareness Day in California.

Fiscal committee: no.

- 1 WHEREAS, There are one in 2,229 individuals born with
2 gastroschisis in the United States and roughly the same number
3 born in California annually; and
4 WHEREAS, While this disease may affect small numbers of
5 people, gastroschisis affects many Americans; and
6 WHEREAS, Many Americans living with gastroschisis have
7 serious and debilitating conditions that have a significant impact
8 on the lives of those affected, including, but not limited to, failure
9 to thrive or slow growth, short bowel syndrome, multiple organ
10 transplants, and long-term feeding issues; and
11 WHEREAS, Individuals and families affected by gastroschisis
12 often experience problems such as a sense of isolation, difficulty
13 in obtaining an accurate and timely diagnosis, few treatment
14 options, and problems related to accessing or being reimbursed
15 for treatment; and
16 WHEREAS, The cause of gastroschisis is relatively unknown,
17 and patients and their families must bear a large share of the burden
18 for things such as raising funds for research; and

1 WHEREAS, Hundreds of residents in California are among
2 those affected by gastroschisis; and

3 WHEREAS, Avery’s Angels Gastroschisis Foundation (AAGF)
4 is organizing a nationwide observance of Gastroschisis Awareness
5 Day on July 30, 2016, and every year thereafter; and

6 WHEREAS, AAGF is based in Raleigh, North Carolina, and is
7 the only nonprofit organization for gastroschisis support
8 nationwide; and

9 WHEREAS, The founder of AAGF’s son, Avery John Rauen,
10 passed away from complications of his gastroschisis on July 30,
11 2009, at the University of North Carolina Hospital, and this date
12 is to commemorate him and all others who are living with or who
13 are deceased from gastroschisis; and

14 WHEREAS, A statewide proclamation can greatly benefit the
15 families coping with this disease; now, therefore, be it

16 *Resolved by the Senate of the State of California, the Assembly*
17 *thereof concurring,* That the Legislature recognizes July 30, 2016,
18 as Gastroschisis Awareness Day in California; and be it further

19 *Resolved,* That the Secretary of the Senate transmit copies of
20 this resolution to the author for appropriate distribution.