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SCR-133 Gastroschisis Awareness Day. (2015-2016)

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Senate Concurrent Resolution No. 133

CHAPTER 79

Relative to Gastroschisis Awareness Day.

[Filed with Secretary of State July 07, 2016.]

LEGISLATIVE COUNSEL'S DIGEST

SCR 133, Beall. Gastroschisis Awareness Day.

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

Fiscal Committee: no

WHEREAS, There are one in 2,229 individuals born with gastroschisis in the United States and roughly the same number born in California annually; and

WHEREAS, While this disease may affect small numbers of people, gastroschisis affects many Americans; and

WHEREAS, Many Americans living with gastroschisis have serious and debilitating conditions that have a significant impact on the lives of those affected, including, but not limited to, failure to thrive or slow growth, short bowel syndrome, multiple organ transplants, and long-term feeding issues; and

WHEREAS, Individuals and families affected by gastroschisis often experience problems such as a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

WHEREAS, The cause of gastroschisis is relatively unknown, and patients and their families must bear a large share of the burden for things such as raising funds for research; and

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

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

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

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

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

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

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