Senate Concurrent Resolution No. 162

Introduced by Senator Fuller

August 3, 2016

Senate Concurrent Resolution No. 162—Relative to X-linked adrenoleukodystrophy.

LEGISLATIVE COUNSEL'S DIGEST

SCR 162, as introduced, Fuller. Adrenoleukodystrophy Awareness Month.

This measure would memorialize the month of November 2016 as Adrenoleukodystrophy Awareness Month.

Fiscal committee: no.

WHEREAS, X-linked adrenoleukodystrophy (X-ALD) is one of a group of genetic disorders called the leukodystrophies that cause damage to the myelin sheath, an insulating membrane that surrounds nerve cells in the brain; and

WHEREAS, Women have two X chromosomes and are the carriers of the disease, but men are most severely affected because men only have one X chromosome and lack the protection provided by an extra X chromosome; and

WHEREAS, The loss of myelin and the progressive dysfunction of the adrenal gland are the primary characteristics of X-ALD; and

WHEREAS, X-ALD affects an estimated one in every 20,000 boys, which is roughly 13,600 people in the United States, including boys like Jeremy Hill, Jr. of Bakersfield; and

WHEREAS, While nearly all patients with X-ALD suffer from adrenal insufficiency, also known as Addison's disease, the neurological symptoms can begin either in childhood or adulthood; and

WHEREAS, The childhood cerebral form is the most severe, with onset between four and 10 years of age; and

WHEREAS, The most common symptoms are behavioral changes, including abnormal withdrawal or aggression, poor memory, and poor school performance; and

WHEREAS, Other symptoms include visual loss, learning disabilities, seizures, poorly articulated speech, difficulty swallowing, deafness, disturbances of gait and coordination, fatigue, intermittent vomiting, increased skin pigmentation, and progressive dementia; and

WHEREAS, The milder adult-onset form is known as adrenomyeloneuropathy (AMN), which typically begins between 21 and 35 years of age, and has symptoms that include progressive stiffness, weakness or paralysis of the lower limbs, and ataxia; and

WHEREAS, Almost one-half the women who are carriers of X-ALD will develop a milder form of AMN, but almost never will develop symptoms seen in boys with X-ALD; and

WHEREAS, Treatment with adrenal hormones can be lifesaving, and symptomatic and supportive treatments for X-ALD include physical therapy, psychological support, and special education; and

WHEREAS, Newborn screening is effective in catching and preventing the negative effects of X-ALD and is relatively inexpensive; and

WHEREAS, The prognosis for patients with childhood cerebral X-ALD is generally poor due to progressive neurological deterioration, unless bone marrow transplantation is performed early; and

WHEREAS, Recent evidence suggests that a mixture of oleic acid and erucic acid, known as "Lorenzo's Oil," administered to boys with X-ALD prior to the onset of symptoms can prevent or delay, but not stop, the appearance of the childhood cerebral form of X-ALD; and

WHEREAS, Death usually occurs between one and 10 years after the onset of symptoms of childhood cerebral X-ALD, and in adult-onset AMN deterioration will progress over decades; and

WHEREAS, November, the month of Jeremy Hill, Jr.'s birthday, was chosen to acknowledge the struggles of Jeremy Hill, Jr., his parents, Jeremy and Debra Hill, and his sister, Meagan Hill, in fighting X-ALD; now, therefore, be it

Resolved by the Senate of the State of California, the Assembly thereof concurring, That the Legislature does hereby proclaim the month of November 2016 as Adrenoleukodystrophy Awareness Month; and be it further

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

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