
THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 1147 Session of
2018

INTRODUCED BY SCHLOSSBERG, BIZZARRO, BURNS, DIGIROLAMO,
HENNESSEY, HILL-EVANS, LONGIETTI, MILLARD, NEILSON,
PASHINSKI, READSHAW, ROZZI, RYAN, SCHWEYER, THOMAS,
YOUNGBLOOD AND PHILLIPS-HILL, OCTOBER 9, 2018

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35,
OCTOBER 9, 2018

A RESOLUTION

1 Designating the month of November 2018 as "Adrenoleukodystrophy
2 Awareness Month" in Pennsylvania.

3 WHEREAS, Adrenoleukodystrophy (ALD) is a deadly genetic
4 condition that damages the membrane insulating the nerve cells
5 in the human brain; and

6 WHEREAS, Affecting 1 in 18,000 individuals, ALD causes very
7 long chain fatty acids (VLCFAs) to build up in the brain,
8 nervous system and adrenal gland as a result of the body's
9 inability to break down the VLCFAs; and

10 WHEREAS, Though it knows no racial, ethnic, nor geographic
11 boundaries, the most common type of ALD affects the X chromosome
12 and is carried unknowingly by women; and

13 WHEREAS, While females can display symptoms of the disorder,
14 ALD severely affects boys and men; and

15 WHEREAS, The most devastating form of ALD appears in
16 childhood, generally between 4 and 10 years of age; and

1 WHEREAS, ALD gradually ravages the brain and leads to
2 blindness, deafness, seizures, loss of muscle control and
3 progressive dementia, resulting in death or permanent
4 disability, usually within two to five years from the point of
5 diagnosis; and

6 WHEREAS, The best hope for those with ALD is early detection
7 through newborn screening to allow for treatment; and

8 WHEREAS, Bone marrow transplants have been shown to be an
9 effective treatment for ALD when diagnosis is made early; and

10 WHEREAS, ALD affects men two to three times more often than
11 women; and

12 WHEREAS, "Adrenoleukodystrophy Awareness Month" will increase
13 the public's awareness of ALD patients' circumstances,
14 acknowledge the terrible impact this disease has on patients and
15 their families and recognize the need for research and treatment
16 to eradicate ALD; therefore be it

17 RESOLVED, That the House of Representatives designate the
18 month of November 2018 as "Adrenoleukodystrophy Awareness Month"
19 in Pennsylvania.