

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE RESOLUTION

No. 755 Session of
2012

INTRODUCED BY GEIST, STERN, BAKER, BRENNAN, D. COSTA, EVERETT,
GEORGE, GODSHALL, GROVE, HARHART, HESS, HICKERNELL, KORTZ,
LONGIETTI, MARSICO, MILLARD, MOUL, READSHAW, ROCK, ROSS,
SANTONI, SAYLOR, SCAVELLO, SCHMOTZER, SONNEY, STABACK, VEREB,
VULAKOVICH, YOUNGBLOOD, O'NEILL, FLECK, KNOWLES AND MAHONEY,
JUNE 5, 2012

INTRODUCED AS NONCONTROVERSIAL RESOLUTION UNDER RULE 35, JUNE 5,
2012

A RESOLUTION

1 Recognizing the month of August 2012 as "Adrenoleukodystrophy
2 Awareness Month" in Pennsylvania and encouraging research on
3 adrenoleukodystrophy to be conducted.

4 WHEREAS, Adrenoleukodystrophy (ALD) is an X-linked genetic
5 disorder that affects the adrenal glands and is characterized by
6 progressive brain and central nervous system deterioration; and

7 WHEREAS, ALD affects mostly males, but some women who are
8 carriers can have milder forms of the disease; and

9 WHEREAS, There are three distinct types of ALD; and

10 WHEREAS, The first type of ALD, childhood cerebral ALD,
11 affects boys between four and ten years of age and affects one
12 in every 17,900 boys worldwide; and

13 WHEREAS, With childhood cerebral ALD, boys develop normally
14 until the onset of symptoms occur, which typically rival those
15 of attention deficit disorder before serious neurological
16 involvement becomes apparent at which time the symptoms progress

1 rapidly and lead to a vegetative state within two years and
2 eventually death; and

3 WHEREAS, The second type of ALD, adrenomyeloneuropathy (AMN),
4 affects otherwise healthy adult males between 20 and 40 years of
5 age; and

6 WHEREAS, AMN affects the spinal cord and leads to symptoms
7 similar to multiple sclerosis which worsen over a period of
8 decades; and

9 WHEREAS, Thirty-five percent of men affected by AMN develop
10 cerebral symptoms similar to childhood cerebral ALD which lead
11 to death in just a few short years; and

12 WHEREAS, The third type of ALD, Addison's disease, affects
13 all age groups and can be life threatening; and

14 WHEREAS, With Addison's disease, adrenal glands produce too
15 little cortisol as well as insufficient levels of aldosterone;
16 and

17 WHEREAS, ALD is more widespread than amyotrophic lateral
18 sclerosis (ALS), often referred to as "Lou Gehrig's disease";
19 and

20 WHEREAS, Treatment with adrenal hormones can be lifesaving;
21 and

22 WHEREAS, Symptomatic and supportive treatments for ALD
23 include physical therapy, psychological support and special
24 education; and

25 WHEREAS, Two additional treatments, Lorenzo's oil and bone
26 marrow transplantation, appear to be most effective in early
27 stages of the disease but are not effective in later stages of
28 the disease; and

29 WHEREAS, Genetic counseling is recommended for prospective
30 parents with a family history of ALD; and

1 WHEREAS, Prenatal diagnosis of ALD is also available; and
2 WHEREAS, Increasing awareness and understanding of ALD and
3 promoting research on the disease will help children and adults
4 with ALD be identified as early as possible when there is the
5 best hope of a beneficial treatment; therefore be it

6 RESOLVED, That the House of Representatives recognize August
7 2012 as "Adrenoleukodystrophy Awareness Month" in Pennsylvania
8 and encourage research on adrenoleukodystrophy to be conducted.