

---

THE GENERAL ASSEMBLY OF PENNSYLVANIA

---

# HOUSE RESOLUTION

No. 251 Session of  
2023

---

INTRODUCED BY BRENNAN, BARTON, SCHLEGEL, TWARDZIK, HILL-EVANS,  
GALLAGHER, MADDEN, DONAHUE, KHAN, SCHLOSSBERG, NEILSON,  
MARCELL, ROZZI, STEHR, WATRO, T. DAVIS, CEPEDA-FREYTIZ,  
FLICK, BANTA, JOZWIAK AND KAZEEM, OCTOBER 27, 2023

---

REFERRED TO COMMITTEE ON HEALTH, OCTOBER 27, 2023

---

A RESOLUTION

1 Recognizing the month of May 2024 as "ALSP Awareness Month" in  
2 Pennsylvania.

3 WHEREAS, Adult-onset leukoencephalopathy with axonal  
4 spheroids and pigmented glia (ALSP) is a rare neurological  
5 disease that is passed genetically from parent to child; and

6 WHEREAS, A parent with the mutated gene has a 50% chance of  
7 passing the mutation to the parent's child; and

8 WHEREAS, ALSP affects both men and women and typically  
9 exhibits symptoms between the ages of 30 and 50; and

10 WHEREAS, Symptoms of ALSP may include a decline in mobility  
11 and psychological changes such as forgetfulness, loss of speech  
12 and mood changes; and

13 WHEREAS, Other physical symptoms of ALSP include muscle  
14 spasms, a reduced feeling for pain and touch and an inability to  
15 hold posture; and

16 WHEREAS, Because of similar symptoms, this disease may be  
17 misdiagnosed as another disease such as frontal lobe dementia,

1 Parkinson's disease or primary progressive multiple sclerosis;  
2 and

3 WHEREAS, While the estimated number of people thought to have  
4 ALSP in the United States is 10,000, the exact number of cases  
5 of this disorder is unknown; and

6 WHEREAS, It is difficult to record the exact number of ALSP  
7 cases, partially because of misdiagnoses and also because the  
8 majority of those with the mutated gene do not know they have it  
9 until they experience symptoms; and

10 WHEREAS, To be formally diagnosed as having ALSP, genetic  
11 testing is necessary; and

12 WHEREAS, The current treatment options for ALSP are extremely  
13 limited, with no FDA-approved therapies available; and

14 WHEREAS, ALSP often does not present itself until a person is  
15 in their forties and has already passed it to their children;  
16 and

17 WHEREAS, The Sisters' Hope Foundation is a nonprofit  
18 organization that raises awareness and understanding of ALSP and  
19 supports those living with or caring for those living with ALSP,  
20 fighting for the mission of seeing the first survivor of ALSP;  
21 and

22 WHEREAS, The Sisters' Hope Foundation creates resources and  
23 connections within the ALSP community and offers financial  
24 support to those who have the disease; and

25 WHEREAS, The Sisters' Hope Foundation encourages those with a  
26 family history of ALSP to undergo a genetic test so that they  
27 have the option in participating in treatments, clinical trials  
28 and research that will help to find a cure; and

29 WHEREAS, It is important that awareness be raised surrounding  
30 this deadly disease, which may also help families recognize

1 patterns in their family history and perhaps realize that  
2 seemingly unconnected illnesses were part of a larger pattern  
3 caused by this disease; therefore be it

4       RESOLVED, That the House of Representatives recognize the  
5 month of May 2024 as "ALSP Awareness Month" in Pennsylvania.