

THE GENERAL ASSEMBLY OF PENNSYLVANIA

# SENATE RESOLUTION

No. 168 Session of  
2013

INTRODUCED BY FOLMER, DINNIMAN, TOMLINSON, WOZNIAK, SOLOBAY,  
GREENLEAF, FERLO, ROBBINS, STACK, ALLOWAY, FONTANA, SMITH,  
ERICKSON, BROWNE, HUTCHINSON, RAFFERTY, PILEGGI, VULAKOVICH,  
COSTA, WAUGH AND WHITE, JUNE 24, 2013

INTRODUCED AND ADOPTED, JUNE 24, 2013

## A RESOLUTION

1 Recognizing June 24, 2013, as "Smith-Lemli-Opitz Syndrome  
2 Awareness Day" in Pennsylvania.

3 WHEREAS, The Smith-Lemli-Opitz/RSH Syndrome (SLO/RSH) is a  
4 recessive genetic metabolic disorder that affects the  
5 development of children before and after birth; and

6 WHEREAS, Geneticists have determined that a recessive gene  
7 blocks cholesterol metabolism in fetuses and children, causing  
8 SLO/RSH manifestations and certain supplementary cholesterol  
9 treatments are still in early research stages, but appear  
10 encouraging; and

11 WHEREAS, Almost all SLO/RSH children are born with small  
12 brains and have varying degrees of slow development and  
13 intellectual disability; and

14 WHEREAS, Children with SLO/RSH have trouble making and using  
15 cholesterol, which affects their growth, weight and cognitive  
16 development; and

17 WHEREAS, Children's lifespan can be limited by serious

1 internal malformations, but with proper nutrition and  
2 consultation with medical professionals, children with SLO/RSH  
3 can often have a normal lifespan, and may learn to walk and  
4 talk; and

5 WHEREAS, According to the Smith-Lemli-Opitz/RSH Foundation,  
6 the syndrome affects one in every 20,000 to 40,000 births,  
7 including at least 40 families in Pennsylvania; and

8 WHEREAS, Carrier testing is now possible by measurement of 7-  
9 dehydrocholesterol or enzyme levels in cultured cells, and a more  
10 accurate DNA test is anticipated; therefore be it

11 RESOLVED, That the Senate recognize June 24, 2013, as "Smith-  
12 Lemli-Opitz Syndrome Awareness Day" in Pennsylvania.