



HR0342

LRB101 12284 ALS 60045 r

1 HOUSE RESOLUTION

2 WHEREAS, The Illinois House of Representatives wishes to  
3 raise awareness surrounding the rare disease of Spinal Muscular  
4 Atrophy; and

5 WHEREAS, Spinal Muscular Atrophy is a degenerative,  
6 genetic neurological condition that affects and prevents  
7 motor-control neurons from sending signals from the central  
8 nervous system to the body's muscles that, in turn, causes the  
9 loss of muscle control and ultimately muscle wasting; and

10 WHEREAS, Spinal Muscular Atrophy is a rare genetic  
11 neuromuscular disease; and

12 WHEREAS, In the United States, an estimated one in 11,000  
13 babies are born with spinal muscular atrophy; and

14 WHEREAS, There are four types of spinal muscular atrophy,  
15 the most severe of which may require a ventilator and feeding  
16 tubes; and

17 WHEREAS, Spinal muscular atrophy affects everyone  
18 differently, and symptoms can vary greatly according to the age  
19 of onset and the severity of the disease; and

1           WHEREAS, Those who suffer from spinal muscular atrophy have  
2 normally developed brains and are bright, sensitive, and full  
3 of life despite their diagnosis; and

4           WHEREAS, Unlike many other rare neuromuscular diseases,  
5 there is a clear understanding of the specific genetic cause of  
6 spinal muscular atrophy; and

7           WHEREAS, Ongoing research offers the promise that a cure  
8 for spinal muscular atrophy may one day be found; and

9           WHEREAS, Increased awareness of spinal muscular atrophy  
10 will lead to increased knowledge and increased support for both  
11 disease research and the families affected by the disease;  
12 therefore, be it

13           RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE ONE  
14 HUNDRED FIRST GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, that  
15 we declare August 2019 as Spinal Muscular Atrophy Awareness  
16 Month in the State of Illinois, and we encourage continuing  
17 research on Spinal Muscular Atrophy and community support for  
18 those affected with the disease.