

1 HOUSE JOINT RESOLUTION

2 WHEREAS, The General Assembly supports a newborn
3 screening program that tests for certain inborn disorders
4 that can result in early mortality or a lifelong disability
5 if left undetected; and

6 WHEREAS, These detectable disorders include metabolic
7 disorders, hematologic disorders, and endocrinopathies that
8 account for approximately 3,000 new cases of potentially
9 fatal or debilitating diseases each year for which outcomes
10 are improved with early identification and treatment through
11 newborn screening systems; and

12 WHEREAS, A recent national report released in August 2000
13 by the federal Health Resources and Services Administration
14 and the American Academy of Pediatrics found that state
15 newborn screening systems need to be both modernized and
16 standardized; and

17 WHEREAS, Every state requires newborns be tested for
18 phenylketonuria (PKU) and hypothyroidism, but state screening
19 programs may test anywhere from the required 2 diseases up to
20 a total of 35 diseases; and

21 WHEREAS, The development of new technology known as
22 tandem mass spectrometry allows infants to be tested for 30
23 diseases or more at a cost of \$25 or less; and

24 WHEREAS, The District of Columbia, Maine, Massachusetts,
25 North Carolina, Rhode Island, and Wisconsin all currently
26 utilize tandem mass spectrometry in their state newborn
27 screening programs; and

28 WHEREAS, Illinois currently requires screening for 6
29 disorders, including biotinidase deficiency, congenital
30 adrenal hyperplasia, congenital hypothyroidism, galactosemia,
31 phenylketonuria (PKU), and sickle cell disease; and

1 WHEREAS, Illinois recently purchased 2 tandem mass
2 spectrometers and is currently conducting pilot studies,
3 while the Genetic and Metabolic Diseases Advisory Committee
4 is working on developing follow-up recommendations for
5 expanding the State's Newborn Screening Program; therefore,
6 be it

7 RESOLVED, BY THE HOUSE OF REPRESENTATIVES OF THE
8 NINETY-SECOND GENERAL ASSEMBLY OF THE STATE OF ILLINOIS, THE
9 SENATE CONCURRING HEREIN, that we urge the Director of Public
10 Health and the Administrator of the Newborn Screening Program
11 to take appropriate action in disseminating information to
12 the parents and family members of newborns regarding all of
13 the inborn disorders that may be detected through newborn
14 screening; and be it further

15 RESOLVED, That this information shall include details
16 regarding the symptoms of each disorder, the health
17 implications if these disorders are left untreated, and the
18 treatment that is available for each of these disorders; and
19 be it further

20 RESOLVED, That the General Assembly commends the Illinois
21 Department of Public Health for its Newborn Screening Program
22 and encourages the Department to continue with the tandem
23 mass spectrometry pilot studies; and be it further

24 RESOLVED, That the General Assembly urges the Genetic and
25 Metabolic Diseases Advisory Committee to give full
26 consideration to expanding the list of disorders included
27 under the State's Newborn Screening Program; and be it
28 further

29 RESOLVED, That suitable copies of this resolution be
30 delivered to the Director of Public Health, the Administrator
31 of the Newborn Screening Program, and the members of the
32 Genetic and Metabolic Diseases Advisory Committee.