FIFTEENTH CONGRESS OF THE REPUBLIC OF THE PHILIPPINES First Regular Session

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Introduced by Senator Antonio "Sonny" F. Trillanes IV

EXPLANATORY NOTE

Republic Act 9288, otherwise known as the Newborn Screening Act of 2004, illustrates a procedure to detect a genetic and metabolic disorder in newborns that may lead to mental retardation and even death if left untreated.

In many countries, newborn screening has been a mechanism that protects babies from health risks. In our country, the rules and regulations implementing the Newborn Screening Act recommended the conditions to be included in the newborn screening panel of disorders.

According to the Philippine Pediatrics Society, the advancement of newborn screening has succeeded in reducing morbidity and mortality associated with certain congenital disorders as it allows timely medical intervention for diagnosed patients. Affected children identified through newborn screening can lead normal lives with the help of prompt and appropriate medical management¹.

Recognizing the importance of newborn screening, this bill expands the number of disorders for which newborn infants in the country are required to be tested by law. Specifically, this bill provides for the expansion of the prescribed list of disorders for which testing is required under the implementing rules and regulations of R.A. 9288.

In view of the foregoing, the immediate approval of this bill is earnestly sought.

'ONIO "SONNY " F. TRILLANES IV

Senator

¹ National Newborn Screening Society of the Philippines. Data retrieved at <u>http://www.pps.org.ph/policy_statements/screening_inborn_errors.pdf</u> on 11 March 2009

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Introduced by Senator Antonio "Sonny" F. Trillanes IV

AN ACT

EXPANDING THE NUMBER OF DISORDERS INCLUDED IN THE NEWBORN SCREENING PROGRAM, AND FOR OTHER PURPOSES

Be it enacted by the Senate and House of Representatives of the Philippines in Congress assembled:

SECTION 1. Short Title. – This Act shall be known as the "Newborn Screening Panel of
 Disorders Act".

3

4 SEC. 2. *Declaration of Policy.* – It is hereby declared the policy of the State that in the 5 interests of public health, every effort should be made to detect in newborn infants, 6 hypothyroidism, galactosemia, phenylketonuria, and other biochemical disorders which may 7 cause mental retardation or other permanent disabilities and to treat the affected individuals.

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9 SEC. 3. Newborn Screening Panel of Disorders. – All infants born in the country shall,
10 pursuant to the Newborn Screening (NBS) Act, be tested for the hereditary disorders such as, but
11 not limited to, the following:

- 12 a) congenital hypothyroidism;
- b) galactosemia;
- 14 c) phenylketonuria;
- 15 d) cystic fibrosis;

1	e) congenital adrenal hyperplasia;
2	f) glucose-6-phosphate dehydrogenase enzyme (G6PDH)
3	g) maple syrup urine disease;
4	h) homocystinuria
5	i) biotinidase deficiency;
6	j) medium chain acyl CoA dehydrogenase deficiency;
7	k) HIVseropositivity;
8	1) sickle cell disease; and
9	m) other blood abnormalities as determined by the Department.
10	The Secretary of the Department of Health, hereinafter referred to as the Secretary, shall
11	issue regulations to assure that newborns are so tested in a manner approved by the same
12	Department. The Secretary shall also ensure that treatment services are available to all identified
13	individuals.
14	The provisions of this Act shall not apply if the parents of a newborn infant object to the
15	testing on the grounds that it would conflict with their religious tenets or practices.
16	
17	SEC. 4. Tasks of the Department of Health The Department of Health, hereinafter
18	referred to as the Department, shall perform the following tasks:
19	a) may charge a reasonable fee for the tests performed pursuant to this Act, and
20	determine the procedures for collecting such;
21	b) shall apply all revenues collected from the fees to the testing and treatment
22	procedures performed pursuant to this Act;

- c) may also require testing of newborn infants for other preventable biochemical disorders if reliable and efficient testing techniques are available;
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d) shall provide a program of reviewing and following up on positive cases in order that measures may be taken to prevent mental retardation or other permanent disabilities;

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e) shall conduct an intensive educational and training program among physicians, hospitals, public health nurses and the public concerning biochemical disorders.

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8 SEC. 5. Information Related to Disorders in the NBS . – Information on newborn 9 infants and their families compiled pursuant to this Act may be used by the Department and 10 agencies designated by the Secretary for the purposes of carrying out this Act; otherwise, the 11 information shall be confidential and not divulged or made public so as to disclose the identity of 12 any person to which it relates, except as provided by law. The program indicated in Section 3 (d) 13 shall include information concerning the nature of the disorders, testing for the detection of these 14 disorders and treatment modalities for these disorders.

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SEC. 6. Separability Clause. – If any provision of this Act shall at any time be found to
 be unconstitutional or invalid, the remainder thereof not affected by such declaration shall
 remain in full force and effect.

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SEC: 7. *Repealing Clause*. – All laws, decrees, rules or regulations inconsistent with the
 provisions of this Act are hereby repealed or modified accordingly.

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- 23 SEC. 8. *Effectivity Clause*. This Act shall take effect after fifteen (15) days following
 24 its complete publication in two (2) newspapers of general circulation.

Approved,