## Illinois

### Newborn Genetic Testing and Surveillance System

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| IL    | STATUTE: 410 ILCS 240 | **410 ILCS 240 Sec. 0.01** Short title. This Act may be cited as the Newborn Metabolic Screening Act. | **410 ILCS 240 Sec. 3** The provisions of this Act shall not apply when parent or guardian of the child objects thereto on the grounds that such test conflicts with his religious tenets and practices. A written statement of such objection shall be presented to the physician or other person whose duty it is to administer and report such tests under the provisions of this Act. | JCAR 77 - Section 840.200 Adverse Pregnancy Outcome An adverse pregnancy outcome for an infant consists of one or more of the following case criterion: ...(e) (3) Endocrine, metabolic or immune disorder: 
(A) Hypothyroidism (ICD-9-CM 243); 
(B) Adrenogenital syndrome (ICD-9-CM 255.2); 
(C) *Inborn errors of metabolism* (ICD-9-CM 270-273, 275-276); 
D) Cystic fibrosis (ICD-9-CM 277.0); or 
E) Immune deficiency disorder | NO | YES religious |
|       | RULES: JCAR Title 77, Ch I, Sub Cpt I, Part 661, Section 661.50, 661.60, 840.200 and 840.30 | **410 ILCS 240 Sec. 1** The Illinois Department of Public Health shall promulgate and enforce rules and regulations requiring that every newborn be subjected to tests for phenylketonuria, hypothyroidism, galactosemia and such other metabolic diseases as the Department may deem necessary from time to time. The Department is empowered to promulgate such additional rules and regulations as are found necessary for the administration of this Act, including mandatory reporting of the results of all tests for these conditions to the Illinois Department of Public Health. | | | | |
In accordance with the timetable specified in this subsection, provide all newborns with expanded screening tests for the presence of certain Lysosomal Storage Disorders known as Krabbe, Pompe, Gaucher, Fabry, and Niemann-Pick…

**JCAR 77 - Section 661.50 Diagnosis and Treatment.** The Department shall also maintain a registry to record the results of diagnosis and treatment for all diagnosed cases identified. It is imperative to perform ongoing evaluation of the newborn screening program. This process includes outcome evaluation of children diagnosed through newborn

| (a-6) In accordance with the timetable specified in this subsection, provide all newborns with expanded screening tests for the presence of certain Lysosomal Storage Disorders known as Krabbe, Pompe, Gaucher, Fabry, and Niemann-Pick… | (b) maintain a registry of cases including information of importance for the purpose of follow-up services to prevent mental retardation… | (e) Require that all specimens collected pursuant to this Act or the rules and regulations promulgated hereunder be submitted for testing to the nearest Department of Public Health laboratory designated to perform such tests… |

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**Objection based on religious tenets and practices is the only ground for exemption.** The Department shall

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**JCAR 77 - Section 661.60 Exemption.** Whenever a newborn screening test is not performed because a parent or guardian presents a written statement of objection on the basis of religious tenets and practices, documentation shall be maintained by the facility of birth or by the primary health care provider.

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**JCAR 77 - Section 840.30 Availability of [Health and Hazardous Substances] Registry Information:** …(b) All requests by medical or epidemiologic researchers for confidential Registry data must be submitted in writing to the Department…

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(d)(1) The Department will enter into research agreements for all approved research requests…

(k) Every reporting facility shall provide access to diagnostic, treatment, follow-up and survival information regarding specified patients or other patients specified through rapid case
screening. The Department shall request, from the medical specialist or primary care provider, updated information annually, concerning developmental milestones, for each child diagnosed with a disorder for which the Department screens.

be notified in writing.

ascertainment for research studies conducted by the Department.

410 ILCS 240 Sec. 2

…(e)… Nothing in this Act shall be construed to prohibit any licensed medical facility from collecting additional specimens for testing for metabolic or neonatal diseases or any other diseases or conditions, as it deems fit.