1 AN ACT concerning health.

## Be it enacted by the People of the State of Illinois, represented in the General Assembly:

- Section 5. The Illinois Administrative Procedure Act is amended by changing Section 5-45 as follows:
- 6 (5 ILCS 100/5-45) (from Ch. 127, par. 1005-45)
- 7 Sec. 5-45. Emergency rulemaking.

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- 8 (a) "Emergency" means the existence of any situation that
  9 any agency finds reasonably constitutes a threat to the public
  10 interest, safety, or welfare.
  - (b) If any agency finds that an emergency exists that requires adoption of a rule upon fewer days than is required by Section 5-40 and states in writing its reasons for that finding, the agency may adopt an emergency rule without prior notice or hearing upon filing a notice of emergency rulemaking with the Secretary of State under Section 5-70. The notice shall include the text of the emergency rule and shall be published in the Illinois Register. Consent orders or other court orders adopting settlements negotiated by an agency may adopted under this Section. Subject to applicable constitutional or statutory provisions, an emergency rule becomes effective immediately upon filing under Section 5-65 or at a stated date less than 10 days thereafter. The agency's

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finding and a statement of the specific reasons for the finding shall be filed with the rule. The agency shall take reasonable and appropriate measures to make emergency rules known to the persons who may be affected by them.

(c) An emergency rule may be effective for a period of not longer than 150 days, but the agency's authority to adopt an identical rule under Section 5-40 is not precluded. emergency rule may be adopted more than once in any 24-month period, except that this limitation on the number of emergency rules that may be adopted in a 24-month period does not apply to (i) emergency rules that make additions to and deletions from the Drug Manual under Section 5-5.16 of the Illinois Public Aid Code or the generic drug formulary under Section 3.14 of the Illinois Food, Drug and Cosmetic Act, (ii) emergency rules adopted by the Pollution Control Board before July 1, 1997 to implement portions of the Livestock Management Facilities Act, (iii) emergency rules adopted by the Illinois Department of Public Health under subsections (a) through (i) of Section 2 of the Department of Public Health Act when necessary to protect the public's health, (iv) emergency rules adopted pursuant to subsection (n) of this Section, (v) emergency rules adopted pursuant to subsection (o) of this Section, or (vi) emergency rules adopted pursuant to subsection (c-5) of this Section. Two or more emergency rules having substantially the same purpose and effect shall be deemed to be a single rule for purposes of this Section.

- (c-5) To facilitate the maintenance of the program of group health benefits provided to annuitants, survivors, and retired employees under the State Employees Group Insurance Act of 1971, rules to alter the contributions to be paid by the State, annuitants, survivors, retired employees, or any combination of those entities, for that program of group health benefits, shall be adopted as emergency rules. The adoption of those rules shall be considered an emergency and necessary for the public interest, safety, and welfare.
- (d) In order to provide for the expeditious and timely implementation of the State's fiscal year 1999 budget, emergency rules to implement any provision of Public Act 90-587 or 90-588 or any other budget initiative for fiscal year 1999 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative, except that the 24-month limitation on the adoption of emergency rules and the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (d). The adoption of emergency rules authorized by this subsection (d) shall be deemed to be necessary for the public interest, safety, and welfare.
- (e) In order to provide for the expeditious and timely implementation of the State's fiscal year 2000 budget, emergency rules to implement any provision of Public Act 91-24 or any other budget initiative for fiscal year 2000 may be adopted in accordance with this Section by the agency charged

- with administering that provision or initiative, except that the 24-month limitation on the adoption of emergency rules and the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (e). The adoption of emergency rules authorized by this subsection (e) shall be deemed to be necessary for the public interest, safety, and welfare.
  - implementation of the State's fiscal year 2001 budget, emergency rules to implement any provision of Public Act 91-712 or any other budget initiative for fiscal year 2001 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative, except that the 24-month limitation on the adoption of emergency rules and the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (f). The adoption of emergency rules authorized by this subsection (f) shall be deemed to be necessary for the public interest, safety, and welfare.
  - (g) In order to provide for the expeditious and timely implementation of the State's fiscal year 2002 budget, emergency rules to implement any provision of Public Act 92-10 or any other budget initiative for fiscal year 2002 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative, except that the 24-month limitation on the adoption of emergency rules and

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- 1 the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (q). The adoption of emergency rules authorized by this subsection (g) shall be deemed to be necessary for the public interest, safety, and welfare.
  - (h) In order to provide for the expeditious and timely implementation of the State's fiscal year 2003 budget, emergency rules to implement any provision of Public Act 92-597 or any other budget initiative for fiscal year 2003 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative, except that the 24-month limitation on the adoption of emergency rules and the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (h). The adoption of emergency rules authorized by this subsection (h) shall be deemed to be necessary for the public interest, safety, and welfare.
  - (i) In order to provide for the expeditious and timely implementation of the State's fiscal year 2004 budget, emergency rules to implement any provision of Public Act 93-20 or any other budget initiative for fiscal year 2004 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative, except that the 24-month limitation on the adoption of emergency rules and the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (i). The adoption of

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- emergency rules authorized by this subsection (i) shall be deemed to be necessary for the public interest, safety, and welfare.
  - (j) In order to provide for the expeditious and timely implementation of the provisions of the State's fiscal year 2005 budget as provided under the Fiscal Year 2005 Budget Implementation (Human Services) Act, emergency rules to implement any provision of the Fiscal Year 2005 Budget Implementation (Human Services) Act may be adopted in accordance with this Section by the agency charged with administering that provision, except that the 24-month limitation on the adoption of emergency rules and the provisions of Sections 5-115 and 5-125 do not apply to rules adopted under this subsection (j). The Department of Public Aid may also adopt rules under this subsection (j) necessary to administer the Illinois Public Aid Code and the Children's Health Insurance Program Act. The adoption of emergency rules authorized by this subsection (j) shall be deemed to be necessary for the public interest, safety, and welfare.
  - (k) In order to provide for the expeditious and timely implementation of the provisions of the State's fiscal year 2006 budget, emergency rules to implement any provision of Public Act 94-48 or any other budget initiative for fiscal year 2006 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative, except that the 24-month limitation on the adoption

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- of emergency rules and the provisions of Sections 5-115 and 1 2 5-125 do not apply to rules adopted under this subsection (k). The Department of Healthcare and Family Services may also adopt 3 rules under this subsection (k) necessary to administer the 5 Illinois Public Aid Code, the Senior Citizens and Persons with Disabilities Property Tax Relief Act, the Senior Citizens and 6 7 Disabled Persons Prescription Drug Discount Program Act (now 8 the Illinois Prescription Drug Discount Program Act), and the 9 Children's Health Insurance Program Act. The adoption of 10 emergency rules authorized by this subsection (k) shall be 11 deemed to be necessary for the public interest, safety, and 12 welfare.
  - (1) In order to provide for the expeditious and timely implementation of the provisions of the State's fiscal year 2007 budget, the Department of Healthcare and Family Services may adopt emergency rules during fiscal year 2007, including rules effective July 1, 2007, in accordance with this subsection to the extent necessary to administer the Department's responsibilities with respect to amendments to the State plans and Illinois waivers approved by the federal Centers for Medicare and Medicaid Services necessitated by the requirements of Title XIX and Title XXI of the federal Social Security Act. The adoption of emergency rules authorized by this subsection (1) shall be deemed to be necessary for the public interest, safety, and welfare.
    - (m) In order to provide for the expeditious and timely

implementation of the provisions of the State's fiscal year 2008 budget, the Department of Healthcare and Family Services may adopt emergency rules during fiscal year 2008, including rules effective July 1, 2008, in accordance with this subsection to the extent necessary to administer the Department's responsibilities with respect to amendments to the State plans and Illinois waivers approved by the federal Centers for Medicare and Medicaid Services necessitated by the requirements of Title XIX and Title XXI of the federal Social Security Act. The adoption of emergency rules authorized by this subsection (m) shall be deemed to be necessary for the public interest, safety, and welfare.

- (n) In order to provide for the expeditious and timely implementation of the provisions of the State's fiscal year 2010 budget, emergency rules to implement any provision of Public Act 96-45 or any other budget initiative authorized by the 96th General Assembly for fiscal year 2010 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative. The adoption of emergency rules authorized by this subsection (n) shall be deemed to be necessary for the public interest, safety, and welfare. The rulemaking authority granted in this subsection (n) shall apply only to rules promulgated during Fiscal Year 2010.
- (o) In order to provide for the expeditious and timely implementation of the provisions of the State's fiscal year

- 2011 budget, emergency rules to implement any provision of Public Act 96-958 or any other budget initiative authorized by the 96th General Assembly for fiscal year 2011 may be adopted in accordance with this Section by the agency charged with administering that provision or initiative. The adoption of emergency rules authorized by this subsection (o) is deemed to be necessary for the public interest, safety, and welfare. The rulemaking authority granted in this subsection (o) applies only to rules promulgated on or after July 1, 2010 (the effective date of Public Act 96-958) through June 30, 2011.
- (p) In order to provide for the expeditious and timely implementation of the provisions of Public Act 97-689, emergency rules to implement any provision of Public Act 97-689 may be adopted in accordance with this subsection (p) by the agency charged with administering that provision or initiative. The 150-day limitation of the effective period of emergency rules does not apply to rules adopted under this subsection (p), and the effective period may continue through June 30, 2013. The 24-month limitation on the adoption of emergency rules does not apply to rules adopted under this subsection (p). The adoption of emergency rules authorized by this subsection (p) is deemed to be necessary for the public interest, safety, and welfare.
- (q) In order to provide for the expeditious and timely implementation of the provisions of Articles 7, 8, 9, 11, and 12 of Public Act 98-104, emergency rules to implement any

- provision of Articles 7, 8, 9, 11, and 12 of Public Act 98-104 may be adopted in accordance with this subsection (q) by the agency charged with administering that provision or initiative. The 24-month limitation on the adoption of emergency rules does not apply to rules adopted under this subsection (q). The adoption of emergency rules authorized by this subsection (q) is deemed to be necessary for the public interest, safety, and welfare.
  - (r) In order to provide for the expeditious and timely implementation of the provisions of Public Act 98-651, emergency rules to implement Public Act 98-651 may be adopted in accordance with this subsection (r) by the Department of Healthcare and Family Services. The 24-month limitation on the adoption of emergency rules does not apply to rules adopted under this subsection (r). The adoption of emergency rules authorized by this subsection (r) is deemed to be necessary for the public interest, safety, and welfare.
  - (s) In order to provide for the expeditious and timely implementation of the provisions of Sections 5-5b.1 and 5A-2 of the Illinois Public Aid Code, emergency rules to implement any provision of Section 5-5b.1 or Section 5A-2 of the Illinois Public Aid Code may be adopted in accordance with this subsection (s) by the Department of Healthcare and Family Services. The rulemaking authority granted in this subsection (s) shall apply only to those rules adopted prior to July 1, 2015. Notwithstanding any other provision of this Section, any

- emergency rule adopted under this subsection (s) shall only
  apply to payments made for State fiscal year 2015. The adoption
  of emergency rules authorized by this subsection (s) is deemed
  to be necessary for the public interest, safety, and welfare.
  - implementation of the provisions of Article II of Public Act 99-6, emergency rules to implement the changes made by Article II of Public Act 99-6 to the Emergency Telephone System Act may be adopted in accordance with this subsection (t) by the Department of State Police. The rulemaking authority granted in this subsection (t) shall apply only to those rules adopted prior to July 1, 2016. The 24-month limitation on the adoption of emergency rules does not apply to rules adopted under this subsection (t). The adoption of emergency rules authorized by this subsection (t) is deemed to be necessary for the public interest, safety, and welfare.
    - (u) In order to provide for the expeditious and timely implementation of the provisions of the Burn Victims Relief Act, emergency rules to implement any provision of the Act may be adopted in accordance with this subsection (u) by the Department of Insurance. The rulemaking authority granted in this subsection (u) shall apply only to those rules adopted prior to December 31, 2015. The adoption of emergency rules authorized by this subsection (u) is deemed to be necessary for the public interest, safety, and welfare.
      - (v) In order to provide for the expeditious and timely

- implementation of the provisions of Public Act 99-516, emergency rules to implement Public Act 99-516 may be adopted in accordance with this subsection (v) by the Department of Healthcare and Family Services. The 24-month limitation on the adoption of emergency rules does not apply to rules adopted under this subsection (v). The adoption of emergency rules authorized by this subsection (v) is deemed to be necessary for the public interest, safety, and welfare.
  - (w) In order to provide for the expeditious and timely implementation of the provisions of Public Act 99-796, emergency rules to implement the changes made by Public Act 99-796 may be adopted in accordance with this subsection (w) by the Adjutant General. The adoption of emergency rules authorized by this subsection (w) is deemed to be necessary for the public interest, safety, and welfare.
  - (x) In order to provide for the expeditious and timely implementation of the provisions of Public Act 99-906, emergency rules to implement subsection (i) of Section 16-115D, subsection (g) of Section 16-128A, and subsection (a) of Section 16-128B of the Public Utilities Act may be adopted in accordance with this subsection (x) by the Illinois Commerce Commission. The rulemaking authority granted in this subsection (x) shall apply only to those rules adopted within 180 days after June 1, 2017 (the effective date of Public Act 99-906). The adoption of emergency rules authorized by this subsection (x) is deemed to be necessary for the public

1 interest, safety, and welfare.

- (y) In order to provide for the expeditious and timely implementation of the provisions of this amendatory Act of the 100th General Assembly, emergency rules to implement the changes made by this amendatory Act of the 100th General Assembly to Section 4.02 of the Illinois Act on Aging, Sections 5.5.4 and 5-5.4i of the Illinois Public Aid Code, Section 55-30 of the Alcoholism and Other Drug Abuse and Dependency Act, and Sections 74 and 75 of the Mental Health and Developmental Disabilities Administrative Act may be adopted in accordance with this subsection (y) by the respective Department. The adoption of emergency rules authorized by this subsection (y) is deemed to be necessary for the public interest, safety, and welfare.
- (z) In order to provide for the expeditious and timely implementation of the provisions of this amendatory Act of the 100th General Assembly, emergency rules to implement the changes made by this amendatory Act of the 100th General Assembly to Section 4.7 of the Lobbyist Registration Act may be adopted in accordance with this subsection (z) by the Secretary of State. The adoption of emergency rules authorized by this subsection (z) is deemed to be necessary for the public interest, safety, and welfare.
- (aa) In order to provide for the expeditious and timely implementation of the provisions of this amendatory Act of the 100th General Assembly, emergency rules to implement the

- 1 changes made by this amendatory Act of the 100th General
- 2 Assembly to Section 3.35 of the Newborn Metabolic Screening Act
- 3 may be adopted in accordance with this subsection (aa) by the
- Secretary of State. The adoption of emergency rules authorized 4
- 5 by this subsection (aa) is deemed to be necessary for the
- public interest, safety, and welfare. 6
- 7 (Source: P.A. 99-2, eff. 3-26-15; 99-6, eff. 1-1-16; 99-143,
- eff. 7-27-15; 99-455, eff. 1-1-16; 99-516, eff. 6-30-16; 8
- 9 99-642, eff. 7-28-16; 99-796, eff. 1-1-17; 99-906, eff. 6-1-17;
- 10 100-23, eff. 7-6-17; 100-554, eff. 11-16-17.)
- 11 Section 10. The Newborn Metabolic Screening Act is amended
- by adding Section 3.35 as follows: 12
- 13 (410 ILCS 240/3.35 new)
- Sec. 3.35. Spinal muscular atrophy. In accordance with the 14
- 15 timetable specified in this Section, the Department shall
- provide all newborns with a screening test for spinal muscular 16
- 17 atrophy using a method that determines the presence or absence
- of the intact or normal SMN1 gene, beginning on the earlier of 18
- 19 the following:
- 20 (1) July 1, 2020; or
- 21 (2) within 6 months following the occurrence of all of
- 22 the following:
- 23 (A) the establishment and verification of relevant
- 24 and appropriate performance specifications as defined

1	under the federal Clinical Laboratory Improvement
2	Amendments and regulations thereunder for federal Food
3	and Drug Administration-cleared or in-house developed
4	methods, performed under an institutional review board
5	approved protocol, if required;
6	(B) the availability of quality assurance
7	materials and comparative threshold values to
8	determine the presence or absence of the intact or
9	normal SMN1 gene;
10	(C) the procurement and installation by the
11	Department of the equipment necessary to implement the
12	initial pilot and statewide volume of screening tests
13	for spinal muscular atrophy;
14	(D) the establishment of precise threshold values
15	ensuring defined disorder identification for spinal
16	<pre>muscular atrophy;</pre>
17	(E) the development and validation of a reliable
18	methodology for screening newborns for spinal muscular
19	atrophy using dried blood spots and quality assurance
20	testing methodology for such test or the approval and
21	procurement of a test for spinal muscular atrophy using
22	dried blood spots by the federal Food and Drug
23	Administration;
24	(F) the authentication of pilot testing achieving
25	each milestone described in subparagraphs (A) through
26	(E) of this paragraph for spinal muscular atrophy; and

(G) the authentication of achieving the potential 1 2 of high throughput standards for statewide volume of 3 spinal muscular atrophy concomitant with each 4 milestone described in subparagraphs (A) through (E)

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The Department is authorized to implement an additional fee for the screening upon the effective date of this amendatory Act of the 100th General Assembly in order to accumulate the resources for start-up and other costs associated with the implementation of the screening and thereafter to support the costs associated with screening. If the Department has not implemented statewide screening for spinal muscular atrophy under this Section within 36 months after the effective date of this amendatory Act of the 100th General Assembly, then the Department shall cease collecting any additional fees related to the screening. The Department may adopt emergency rules in accordance with Section 5-45 of the Illinois Administrative Procedure Act to implement this Section.

Section 99. Effective date. This Act takes effect upon becoming law.