

SECOND REGULAR SESSION

HOUSE BILL NO. 2513

103RD GENERAL ASSEMBLY

INTRODUCED BY REPRESENTATIVE BYRNES.

5089H.02I

JOSEPH ENGLER, Chief Clerk

AN ACT

To amend chapter 191, RSMo, by adding thereto six new sections relating to children with rare or medically complex conditions, with a delayed effective date.

Be it enacted by the General Assembly of the state of Missouri, as follows:

Section A. Chapter 191, RSMo, is amended by adding thereto six new sections, to be
2 known as sections 191.273, 191.276, 191.279, 191.282, 191.285, and 191.288, to read as
3 follows:

191.273. 1. **Sections 191.273 to 191.288 shall be known and may be cited as**
2 **"Maddie's Law: The Rare Pediatric Disease Care and Protocol Protection Act".**
3 2. **As used in sections 191.273 to 191.288, the following terms mean:**
4 (1) **"Caregiver"**, any parent, guardian, or other person having control or
5 custody of a child with a rare or medically complex condition;
6 (2) **"Child"**, any person under eighteen years of age;
7 (3) **"Department"**, the department of health and senior services;
8 (4) **"Emergency services"**, the same meaning given to the term in section
9 **190.100**;
10 (5) **"Health care professional"**, the same meaning given to the term in section
11 **376.1350**;
12 (6) **"Health care provider"**, any hospital as defined in section 197.020,
13 emergency services provider, or other institution providing health care services;
14 (7) **"Health care service"**, the same meaning given to the term in section
15 **376.1350**;

EXPLANATION — Matter enclosed in bold-faced brackets [~~thus~~] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

16 **(8) "Individualized care plan"**, a written, physician-approved plan for the
17 management of acute and chronic manifestations of a child's rare or medically complex
18 condition;

19 **(9) "Protocol deviation"**, any departure from an individualized care plan,
20 emergency protocol, or evidence-based treatment plan for a child with a rare or
21 medically complex condition without documented clinical justification;

22 **(10) "Rare or medically complex condition"**, any condition that:

23 (a) Affects fewer than two hundred thousand individuals in the United States; or
24 (b) Is associated with a high risk of acute deterioration requiring specialized
25 management as documented by a treating physician;

26 **(11) "Significant protocol deviation"**, any protocol deviation that results in harm
27 to the child or that has the potential to result in harm to the child.

191.276. 1. All health care providers for a child with a rare or medically
2 complex condition shall collaborate to develop, document, and maintain an
3 individualized care plan for the child.

4 2. The individualized care plan shall include, at minimum:

5 (1) Clear instructions for emergency care including, but not limited to,
6 medication dosages, routes of administration, and escalation procedures; and

7 (2) Identification of the child's primary specialist responsible for oversight of the
8 plan.

9 3. The child's health care providers shall review and make any necessary
10 changes to the individualized care plan:

11 (1) At least annually; and

12 (2) After any hospitalization of the child. Any review required under this
13 subdivision may count as the annual review required under subdivision (1) of this
14 subsection.

15 4. The individualized care plan shall remain active in all electronic and paper-
16 based health records. Updates to the individualized care plan shall not be made
17 without:

18 (1) The explicit written approval of the primary specialist for the child; and

19 (2) Recognition of the concerns of the child's legal guardian or guardians.

20 5. An emergency services provider shall be considered a health care provider for
21 a child under sections 191.273 to 191.288 if the emergency services provider regularly
22 transports patients to a hospital treating the child. The hospital treating the child shall
23 notify each such emergency services provider of its status as a health care provider for
24 the child under sections 191.273 to 191.288.

191.279. 1. Hospitals and emergency services providers shall maintain logs of:

2 **(1) Adherence to individualized care plans;**
3 **(2) Protocol deviations; and**
4 **(3) Handoffs between emergency services providers and hospital care teams for**
5 **a child with a rare or medically complex condition.**

6 **2. Hospitals and emergency services providers shall create reporting procedures**
7 **to provide documentation of any significant protocol deviations within twenty-four**
8 **hours to:**

9 **(1) The child's primary specialist; and**
10 **(2) The quality and safety officer designated by the hospital.**

11 **191.282. 1. The department shall audit health care providers for compliance**
12 **with sections 191.273 to 191.288 following receipt of reports of noncompliance.**

13 **2. If the department determines that a health care provider has violated any**
14 **provision of sections 191.273 to 191.288, the department may order the health care**
15 **provider to implement a corrective action plan.**

16 **191.285. 1. Each health care provider shall offer and require training on rare**
17 **diseases for all pediatric health care professionals. The training shall include**
18 **instruction on how to recognize high-risk conditions and adhere to individualized**
19 **care plans.**

20 **2. Health care providers are encouraged to maintain a centralized registry of**
21 **individualized care plans for all children with rare or medically complex conditions that**
22 **is accessible to authorized health care professionals and emergency services personnel.**

23 **191.288. 1. A health care provider shall not retaliate against a caregiver for**
24 **advocating for adherence to the individualized care plan or reporting protocol**
25 **deviations.**

26 **2. If systemic failures in implementation of a child's individualized care plan**
27 **occur and a poor outcome would have been avoidable, hospital leadership shall meet**
28 **with the child's caregiver, upon the caregiver's request, for any review of the**
29 **individualized care plan required under section 191.276.**

30 Section B. The enactment of sections 191.273, 191.276, 191.279, 191.282, 191.285,
31 and 191.288 of this act shall become effective on March 1, 2027.