## **101ST GENERAL ASSEMBLY**

# State of Illinois

## 2019 and 2020

#### HB4743

Introduced 2/18/2020, by Rep. Deanne M. Mazzochi

## SYNOPSIS AS INTRODUCED:

New Act 30 ILCS 805/8.44 new

Creates the Patient-Assisted Hemophilia Medication Administration Act. Provides that emergency personnel may assist a patient with a rare blood disease in emergency situations to administer patient-carried medication if the administration meets specified requirements, irrespective of the age of the patient and without the need to secure separate consent from the patient or the patient's caregiver or a legal guardian if the emergency personnel take steps to deliver the patient to a receiving hospital and the receiving hospital is informed of the pending arrival of the rare blood disease patient, along with the treatment instituted by the emergency personnel. Provides an exemption from civil or professional liability. Allows the Department of Public Health to conduct or approve a training program for emergency personnel to recognize and learn additional treatment protocols for rare blood disorders. Amends the State Mandates Act to require implementation without reimbursement.

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FISCAL NOTE ACT MAY APPLY HB4743

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AN ACT concerning health.

# 2 Be it enacted by the People of the State of Illinois, 3 represented in the General Assembly:

Section 1. Short title. This Act may be cited as the
Patient-Assisted Hemophilia Medication Administration Act.

6 Section 5. Findings. The General Assembly finds that:

7 (1) Patients that have rare bleeding disorders such as 8 hemophilia and Von Willebrand Disease can create large 9 demands on health care resources, and such patients necessitate the provision of unique care. Patients with 10 11 these diseases may suffer profuse, life-threatening 12 bleeding even through minor trauma. Patients commonly may recombinant 13 receive human or blood factors 14 prophylactically throughout each week to keep blood factor levels within safe levels. 15

16 (2) During an emergency situation, which may include
17 either a minor or major trauma event, it is the standard of
18 care and opinion of experts that, "if in doubt, treat",
19 preferably within 2 hours.

(3) For severe or life-threatening bleeding, patients
 need appropriate clotting factors by intravenous push over
 one to 2 minutes followed by additional follow up
 prophylactic care.

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(4) Because of the need for immediate treatment, it is 1 common for patients with rare bleeding disorders to carry 2 3 with them at all times their own clotting factor, including, but not limited to, factor VIII, factor IX, and 4 5 Von Willebrand factor; desmopressin; anti-inhibitor 6 coagulant complex; or related substances.

7 The risk of overdose of rare disease blood (5) 8 treatment factors is rare and low relative to the risk of 9 harm to such patients from failure to adequately dose rare 10 blood disease treatment factors if treatment is not 11 administered quickly when an emergency bleed occurs. 12 Failure to treat quickly at the time of trauma may also necessitate increased administration of rare blood disease 13 14 treatment factors for a period of days or weeks compared to 15 normal prophylactic care doses. Treating patients with 16 medication that patients have on hand also lessens the 17 likelihood that a patient will suffer adverse and potentially life-threatening side 18 effects from the 19 generation of alloantibodies, inhibitory antibodies, 20 triggering antibodies, or undesirable binding of HLA class 21 II antigens.

(6) Patients and their associated caregivers who may be
nonmedical personnel, such as parents, are frequently
trained on how to administer rare blood disease treatment
factors to address acute trauma events. However, there may
be times when the caregiver is either not present or

incapacitated; or otherwise solely in the presence of those who have not been trained in how to provide intravenous infusions.

4 (7) Patients and their associated caregivers have 5 experienced failure to immediately treat in response to 6 acute trauma, even when the patient has his or her own 7 rescue medication on hand, because of confusion in the 8 scope of permissible practice.

9 (8) It is the goal of the General Assembly to encourage 10 emergency management technicians, assistant emergency 11 medical technicians, and paramedics certified under 12 Illinois statutes to assist a patient with a rare blood 13 disease in emergency situations.

14 Section 10. Definitions. In this Act:

15 "Administer" means to directly apply, via injector, or 16 deliver, via infusion, a medication associated with a rare 17 blood disease to the body of an individual.

18 "Emergency personnel" includes any emergency medical 19 technician, assistant emergency medical technician, and 20 paramedic licensed under the Emergency Medical Services (EMS) 21 Systems Act.

"Emergency situations" includes at least the following: situations where a call is initiated to or received by 9-1-1 or other emergency response service; events where an emergency medical technician, assistant emergency medical technician, or paramedic has been specially retained to be present; an accident scene; ambulance transport; airlift transport; situations where federal emergency response agencies have been called to a scene; or situations which otherwise arise in a location in the State of Illinois that is not an urgent care center or hospital.

7 "Health care practitioner" means a physician licensed to 8 practice medicine in all its branches under the Medical 9 Practice Act of 1987; a physician assistant under the Physician 10 Assistant Practice Act of 1987 with prescriptive authority; or 11 an advanced practice registered nurse with prescribing 12 authority under Article 65 of the Nurse Practice Act.

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"Patient-carried medication" means:

(1) for a patient who is a resident in the State of
Illinois, medication that has been prescribed by a health
care practitioner in connection with the treatment,
therapy, or prophylactic care of a rare blood disease and
is in the possession, custody, or control of the patient or
the patient's caregiver or legal guardian.

(2) for a patient who is not a resident in the State of
Illinois, medication that has been prescribed by a
physician, physician assistant with prescribing authority,
advanced practice nurse with prescriptive authority who is
licensed in the state of the patient's residency; is in
connection to the treatment, therapy, or prophylactic care
of a rare blood disease; and is in the possession, custody,

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or control of a patient, patient caregiver, or patient's legal guardian; provided that the prescription medication is accompanied by either an original or copy of the prescription signed by an authorizing physician or the packaging indicates the name of a dispensing pharmacy and the prescription was written in the name of the patient.

"Rare blood diseases" means a group of disorders that share 7 8 the inability to form a proper blood clot, characterized by 9 extended bleeding after injury, surgery, trauma, or 10 menstruation, or sometimes spontaneously, without a known or 11 identifiable cause. "Rare blood diseases" includes hemophilia 12 A and B, Von Willebrand Disease, and such additional conditions as may be determined by the Illinois Department of Public 13 Health pursuant to notice and rulemaking. 14

15 "Rare blood disease treatment factors" includes Factor 16 VII; Factor VIII; Factor IX; Von Willebrand factor; desmopressin; anti-inhibitor coagulant complex; complexes, 17 conjugates, or derivatives thereof (including those complexed 18 to polyethylene glycol; genetically modified or synthesized 19 20 variants; or partial fragments of such factors that provide clinical activity); and such additional medications as may be 21 22 determined by the Illinois Department of Public Health pursuant 23 to notice and rulemaking used in the treatment of rare blood 24 disease.

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Section 15. Administering patient-carried medication. Any

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emergency personnel may assist a patient with a rare blood 1 2 disease in emergency situations to administer patient-carried medication if the administration is: 3

(1) consistent with written instructions from an 4 5 authorizing physician, such as a written care plan;

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(2) consistent with the package labeling;

7 (3) via routes of delivery that are within the scope of 8 training of the emergency personnel; or

9 (4) consistent with a care plan that previously was 10 filed by or on behalf of the patient with the chief 11 emergency personnel officer, or his or her designee, 12 provided that the care plan has been independently approved 13 by a health care practitioner.

The activity authorized under this Section may be taken 14 15 irrespective of the age of the patient and without the need to 16 secure separate consent from the patient or the patient's 17 caregiver or a legal guardian if the emergency personnel take steps to deliver the patient to a receiving hospital and the 18 receiving hospital is informed of the pending arrival of the 19 20 rare blood disease patient, along with the treatment instituted 21 by the emergency personnel.

22 Section 20. Liability. When emergency personnel administer 23 patient-carried medication in good faith, the emergency 24 personnel, and their employer, employees, and agents, as well 25 as the health care practitioner or, for out-of-state residents,

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prescribing physician, physician assistant with prescribing 1 2 authority, or advanced practice nurse with prescriptive authority, shall incur no civil or professional liability, 3 4 except for willful and wanton conduct, as a result of any 5 injury or death arising from the assistance of the administration of a patient-carried medication for patients 6 7 with a rare blood disease.

8 Section 25. Training program. The Department of Public 9 Health may conduct or approve a training program for emergency 10 personnel to recognize and learn additional treatment 11 protocols for rare blood disorders.

Section 90. The State Mandates Act is amended by adding Section 8.44 as follows:

14 (30 ILCS 805/8.44 new)

Sec. 8.44. Exempt mandate. Notwithstanding Sections 6 and 8 of this Act, no reimbursement by the State is required for the implementation of any mandate created by this amendatory Act of the 101st General Assembly.