

1 AN ACT concerning health.

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

4 Section 1. Short title. This Act may be cited as the
5 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
10 necessitate the provision of unique care. Patients with
11 these diseases may suffer profuse, life-threatening
12 bleeding even through minor trauma. Patients commonly may
13 receive human or recombinant blood factors
14 prophylactically throughout each week to keep blood factor
15 levels within safe levels.

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.

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

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

7 (5) The risk of overdose of rare disease blood
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
13 necessitate increased administration of rare blood disease
14 treatment factors for a period of days or weeks compared
15 to 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
18 potentially life-threatening side effects from the
19 generation of alloantibodies, inhibitory antibodies,
20 triggering antibodies, or undesirable binding of HLA class
21 II antigens.

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

1 incapacitated, or otherwise solely in the presence of
2 those who have not been trained in how to provide
3 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
10 encourage emergency management technicians, assistant
11 emergency medical technicians, and paramedics certified
12 under Illinois statutes to assist a patient with a rare
13 blood 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.

22 "Emergency situations" includes at least the following:
23 situations where a call is initiated to or received by 9-1-1 or
24 other emergency response service; events where an emergency
25 medical technician, assistant emergency medical technician, or

1 paramedic has been specially retained to be present; an
2 accident scene; ambulance transport; airlift transport;
3 situations where federal emergency response agencies have been
4 called to a scene; or situations which otherwise arise in a
5 location in the State that is not an urgent care center or
6 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
10 Physician Assistant Practice Act of 1987 with prescriptive
11 authority, or an advanced practice registered nurse with
12 prescribing authority under Article 65 of the Nurse Practice
13 Act.

14 "Patient-carried medication" means:

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

21 (2) for a patient who is not a resident in the State,
22 medication that has been prescribed by a physician,
23 physician assistant with prescribing authority, or
24 advanced practice nurse with prescriptive authority who is
25 licensed in the state of the patient's residency, is in
26 connection to the treatment, therapy, or prophylactic care

1 of a rare blood disease, and is in the possession,
2 custody, or control of a patient, patient caregiver, or
3 patient's legal guardian, provided that the prescription
4 medication is accompanied by either an original or copy of
5 the prescription signed by an authorizing physician or the
6 packaging indicates the name of a dispensing pharmacy and
7 the prescription was written in the name of the patient.

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

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

1 Section 15. Administering patient-carried medication. Any
2 emergency personnel may assist a patient with a rare blood
3 disease in emergency situations to administer patient-carried
4 medication if the administration is:

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

7 (2) consistent with the package labeling;

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

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

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

23 Section 20. Training program. The Department of Public
24 Health may conduct or approve a training program for emergency
25 personnel to recognize and learn additional treatment

1 protocols for rare blood disorders.

2 Section 90. The State Mandates Act is amended by adding
3 Section 8.46 as follows:

4 (30 ILCS 805/8.46 new)

5 Sec. 8.46. Exempt mandate. Notwithstanding Sections 6 and
6 8 of this Act, no reimbursement by the State is required for
7 the implementation of any mandate created by this amendatory
8 Act of the 102nd General Assembly.