

ACT No. 57

2019 Regular Session

HOUSE BILL NO. 143

BY REPRESENTATIVES WHITE, CHANEY, ROBERT JOHNSON, MCMAHEN, MOORE, POPE, STAGNI, AND TURNER AND SENATORS ALARIO, ALLAIN, APPEL, BARROW, BISHOP, CARTER, CHABERT, CLAITOR, COLOMB, CORTEZ, ERDEY, FANNIN, GATTI, HENSGENS, HEWITT, JOHNS, LONG, LUNEAU, MARTINY, MILKOVICH, MILLS, MIZELL, MORRELL, PEACOCK, PRICE, RISER, GARY SMITH, TARVER, THOMPSON, WALSWORTH, WARD, AND WHITE

1 AN ACT

2 To enact R.S. 17:2353(M), R.S. 22:1023.1, and Subpart A-1 of Part IV of Subchapter A of
3 Chapter 5-D of Title 40 of the Louisiana Revised Statutes of 1950, to be comprised
4 of R.S. 40:1170.1 through 1170.4, relative to potential recipients of organ
5 transplants; to provide for rights of such persons; to prohibit discrimination against
6 such persons based on disability; to prohibit certain actions by health insurance
7 issuers with respect to organ transplantation; to authorize civil actions for relief in
8 cases of violations of the prohibition on discrimination in organ transplantation; to
9 require courts to follow certain procedures in considering such actions; to provide
10 for definitions; to provide for legislative findings; and to provide for related matters.

11 Be it enacted by the Legislature of Louisiana:

12 Section 1. R.S. 17:2353(M) is hereby enacted to read as follows:

13 §2353. Persons who may receive anatomical gifts; purpose of anatomical gifts

14 * * *

15 M. Potential anatomical gift recipients shall be entitled to the protections
16 against discrimination based on disability provided in R.S. 40:1170.1 et seq.

17 Section 2. R.S. 22:1023.1 is hereby enacted to read as follows:

18 §1023.1. Prohibited discrimination; potential organ transplant recipients with
19 disabilities

20 A. For purposes of this Section, the following terms have the meaning
21 ascribed to them in this Subsection:

1 (1) "Anatomical gift" means a donation of all or part of a human body that
2 takes effect after the death of the donor for the purpose of transplantation or
3 transfusion.

4 (2) "Covered person" means a policyholder, subscriber, enrollee, member,
5 or individual covered by a health benefit plan.

6 (3) "Disability" has the meaning ascribed in 42 U.S.C. 12102.

7 (4) "Health benefit plan" means a policy, contract, certificate, or agreement
8 entered into, offered, or issued by a health insurance issuer to provide, deliver,
9 arrange for, pay for, or reimburse any of the costs of healthcare services. "Health
10 benefit plan" shall not include a plan that provides coverage for excepted benefits as
11 defined in R.S. 22:1061 or short term policies that have a term of less than twelve
12 months.

13 (5) "Health insurance issuer" means an entity subject to the insurance laws
14 and regulations of this state, or subject to the jurisdiction of the commissioner, that
15 contracts or offers to contract to provide, deliver, arrange for, pay for, or reimburse
16 any of the costs of healthcare services, including through a health benefit plan as
17 defined in this Subsection, and shall include a sickness and accident insurance
18 company, a health maintenance organization, a preferred provider organization or
19 any similar entity, or any other entity providing a plan of health insurance or health
20 benefits.

21 (6) "Organ transplant" means the transplantation or transfusion of a part of
22 a human body into the body of another for the purpose of treating or curing a medical
23 condition.

24 B. A health insurance issuer that provides coverage for anatomical gifts,
25 organ transplants, or related treatment and services shall not do any of the following:

26 (1) Deny coverage to a covered person solely on the basis of the person
27 having a disability.

28 (2) Deny to a patient eligibility, or continued eligibility, to enroll or to renew
29 coverage under the terms of the health benefit plan, solely for the purpose of
30 avoiding the requirements of this Section.

1 (3) Penalize or otherwise reduce or limit the reimbursement of an attending
2 provider, or provide monetary or nonmonetary incentives to an attending provider,
3 to induce such provider to furnish care to an insured or enrollee in a manner
4 inconsistent with this Section.

5 (4) Reduce or limit coverage benefits to a patient for the medical services or
6 other services related to organ transplantation performed pursuant to this Section as
7 determined in consultation with the attending physician and patient.

8 C. In the case of a health benefit plan maintained pursuant to one or more
9 collective bargaining agreements between employee representatives and one or more
10 employers, any plan amendment made pursuant to a collective bargaining agreement
11 relating to the plan which amends the plan solely to conform to any requirement
12 imposed pursuant to this Section shall not be treated as a termination of the
13 collective bargaining agreement.

14 D. Nothing in this Section shall be construed as requiring a health insurance
15 issuer to provide coverage for a medically inappropriate organ transplant.

16 Section 3. Subpart A-1 of Part IV of Subchapter A of Chapter 5-D of Title 40 of the
17 Louisiana Revised Statutes of 1950, comprised of R.S. 40:1170.1 through 1170.4, is hereby
18 enacted to read as follows:

19 SUBPART A-1. ORGAN TRANSPLANTATION: RIGHT OF POTENTIAL
20 RECIPIENTS TO NONDISCRIMINATION

21 §1170.1. Legislative findings; declaration

22 A. The legislature hereby finds all of the following:

23 (1) A developmental, intellectual, or physical disability does not diminish
24 a person's right to health care.

25 (2) The provisions of the Americans with Disabilities Act of 1990, as
26 amended (42 U.S.C. 12101 et seq.), prohibit discrimination against persons with
27 disabilities, yet many individuals with disabilities experience discrimination in
28 accessing critical healthcare services.

29 (3) In some cases, persons with developmental, intellectual, or physical
30 disabilities have been denied life-saving organ transplants based on beliefs or

1 assumptions by healthcare providers that those persons are incapable of complying
2 with post-transplant medical requirements, or that they lack adequate support
3 systems to ensure compliance with those medical requirements.

4 (4) Although organ transplant centers must consider medical and
5 psychosocial criteria when determining whether a patient is suitable to receive an
6 organ transplant, transplant centers that participate in Medicare, Medicaid, and other
7 federally funded programs are required to use patient selection criteria that result in
8 a fair and nondiscriminatory distribution of organs.

9 B. The legislature hereby declares that Louisiana residents in need of organ
10 transplants shall be entitled to an assurance that they will not encounter
11 discrimination on the basis of a disability.

12 §1170.2. Definitions

13 For purposes of this Subpart, the following terms have the meaning ascribed
14 to them in this Section:

15 (1) "Anatomical gift" means a donation of all or part of a human body that
16 takes effect after the death of the donor for the purpose of transplantation or
17 transfusion.

18 (2) "Auxiliary aid or service" means an aid or service that is used to provide
19 information to an individual with a cognitive, developmental, intellectual,
20 neurological, or physical disability and is available in a format or manner that allows
21 the individual to better understand the information. An auxiliary aid or service may
22 include any of the following:

23 (a) Qualified interpreters or other effective methods of making aurally
24 delivered materials available to persons who are deaf or hard of hearing.

25 (b) Qualified readers, taped texts, texts in accessible electronic format, or
26 other effective methods of making visually delivered materials available to persons
27 with visual impairments.

28 (c) Supported decision-making services, including all of the following:

1 (i) The use of a support individual to communicate information to the person
2 with a disability, ascertain the wishes of the person, or assist the person in making
3 decisions.

4 (ii) The disclosure of information to a legal guardian, authorized
5 representative, or another individual designated by the person with a disability for
6 such purpose. A person making such disclosure shall do so in conformance with all
7 applicable requirements of state and federal law, including but not limited to those
8 of the Health Insurance Portability and Accountability Act of 1996 (42 U.S.C. 1320d
9 et seq.) and any federal regulations promulgated by the United States Department of
10 Health and Human Services for implementation of that law.

11 (iii) If an individual has a court-appointed guardian or other individual
12 responsible for making medical decisions on behalf of the individual, any measures
13 used to ensure that the individual is included in decisions involving the individual's
14 health care and that medical decisions are in accordance with the individual's own
15 expressed interests.

16 (iv) Any other aid or service that is used to provide information in a format
17 that is easily understandable and accessible to individuals with cognitive,
18 neurological, developmental or intellectual disabilities, including assistive
19 communication technology.

20 (3) "Covered entity" means any of the following entities:

21 (a) Any licensed provider of healthcare services, including licensed
22 healthcare practitioners, hospitals, nursing facilities, laboratories, intermediate care
23 facilities, psychiatric residential treatment facilities, institutions for individuals with
24 intellectual or developmental disabilities, and prison health centers.

25 (b) Any entity responsible for matching anatomical gift donors to potential
26 recipients.

27 (4) "Disability" has the meaning ascribed in 42 U.S.C. 12102.

28 (5) "Organ transplant" means the transplantation or transfusion of a part of
29 a human body into the body of another for the purpose of treating or curing a medical
30 condition.

1 (6)(a) "Qualified recipient" means an individual who has a disability and
2 meets the essential eligibility requirements for the receipt of an anatomical gift.

3 (b) An individual who has a disability and meets the essential eligibility
4 requirements for the receipt of an anatomical gift shall be deemed to be a qualified
5 recipient regardless of any of the following:

6 (i) Whether he has access to individuals or entities available to support and
7 assist him with an anatomical gift or transplantation.

8 (ii) Whether he has access to auxiliary aids or services.

9 (iii) Whether reasonable modifications to the policies, practices, or
10 procedures of a covered entity are implemented, including modifications to allow for
11 either of the following:

12 (aa) Communication with one or more individuals or entities available to
13 support or assist with the recipient's care and medication after surgery or
14 transplantation.

15 (bb) Consideration of support networks available to the individual, including
16 family, friends, and home- and community-based services, including home- and
17 community-based services funded through Medicaid, Medicare, another health plan
18 in which the individual is enrolled, or any program or source of funding available to
19 the individual, when determining whether the individual is able to comply with
20 post-transplant medical requirements.

21 §1170.3. Discrimination against potential organ transplant recipients based on
22 disability; prohibition

23 A. The provisions of this Section shall apply to all stages of the organ
24 transplant process.

25 B. It shall be unlawful for a covered entity to do any of the following solely
26 on the basis of an individual having a disability:

27 (1) Consider the individual ineligible to receive an anatomical gift or organ
28 transplant.

1 (2) Deny medical services or other services related to organ transplantation,
2 including diagnostic services, evaluation, surgery, counseling, and post-operative
3 treatment and services.

4 (3) Refuse to refer the individual to a transplant center or other related
5 specialist for the purpose of being evaluated for or receiving an organ transplant.

6 (4) Refuse to place a qualified recipient on an organ transplant waiting list.

7 (5) Place a qualified recipient on an organ transplant waiting list at a lower
8 priority position than the position at which the individual would have been placed
9 if the individual did not have a disability.

10 (6) Refuse insurance coverage for any procedure associated with being
11 evaluated for or receiving an anatomical gift or organ transplant, including
12 post-transplantation and post-transfusion care.

13 C. Notwithstanding the provisions of Subsection B of this Section, a covered
14 entity may consider an individual's disability when making treatment or coverage
15 recommendations or decisions, but only to the extent that the disability has been
16 found by a physician or surgeon, following an individualized evaluation of the
17 individual, to be medically significant to the provision of the anatomical gift.

18 D. If an individual has the necessary support system to assist him in
19 complying with post-transplant medical requirements, a covered entity may not
20 consider the individual's inability to independently comply with post-transplant
21 medical requirements to be medically significant for the purposes of Subsection C
22 of this Section.

23 E. A covered entity shall make reasonable modifications to its policies,
24 practices, or procedures to allow individuals with disabilities access to
25 transplantation-related services, including diagnostic services, surgery, coverage,
26 post-operative treatment, and counseling, unless the entity can demonstrate that
27 making such modifications would fundamentally alter the nature of such services.

28 F. A covered entity shall take all such actions as are necessary to ensure that
29 an individual with a disability is not denied medical services or other services related
30 to organ transplantation, including diagnostic services, surgery, post-operative

1 treatment, or counseling due to the absence of auxiliary aids or services, unless the
 2 entity demonstrates that taking the actions would fundamentally alter the nature of
 3 such services or would result in an undue burden for the entity.

4 G. Nothing in this Section shall be deemed to require a covered entity to
 5 make a referral or recommendation for or to perform a medically inappropriate organ
 6 transplant.

7 §1170.4. Enforcement; civil actions against covered entities; construction of Section

8 A. Whenever an individual believes that a covered entity has violated or is
 9 violating any provision of R.S. 40:1170.3, the affected individual may commence a
 10 civil action for injunctive and other equitable relief against the covered entity for
 11 purposes of enforcing compliance with this Subpart. The action may be brought in
 12 the district court for the parish where the affected individual resides or resided or
 13 was denied the organ transplant or referral.

14 B. In an action brought under this Section, the court shall give the action
 15 priority on its docket and expedited review, and may grant injunctive or other
 16 equitable relief including by any of the following means:

17 (1) Requiring auxiliary aids or services to be made available for a qualified
 18 recipient.

19 (2) Requiring the modification of a policy, practice, or procedure of a
 20 covered entity.

21 (3) Requiring that facilities be made readily accessible to and usable by a
 22 qualified recipient.

23 C. Nothing in this Section is intended to limit or replace available remedies
 24 under the Americans with Disabilities Act of 1990, as amended (42 U.S.C. 12101 et
 25 seq.), or any other applicable law.

26 D. This Section shall not be construed as creating a right to compensatory
 27 or punitive damages against a covered entity.

28 Section 4.(A) The legislature hereby declares that the life of a person with a
 29 disability who needs an organ transplant is as worthy and valuable as the life of a person
 30 with no disability who needs the same medical service.

1 (B) This Act shall be known and may be cited as "Evie's Law".

2 Section 5. This Act shall become effective upon signature by the governor or, if not
3 signed by the governor, upon expiration of the time for bills to become law without signature
4 by the governor, as provided by Article III, Section 18 of the Constitution of Louisiana. If
5 vetoed by the governor and subsequently approved by the legislature, this Act shall become
6 effective on the day following such approval.

SPEAKER OF THE HOUSE OF REPRESENTATIVES

PRESIDENT OF THE SENATE

GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: _____