HOUSE No. 3271

The Commonwealth of Massachusetts

PRESENTED BY:

James M. Cantwell

To the Honorable Senate and House of Representatives of the Commonwealth of Massachusetts in General Court assembled:

The undersigned legislators and/or citizens respectfully petition for the adoption of the accompanying bill:

An Act concerning nondiscrimination in access to organ transplantation.

PETITION OF:

NAME:	DISTRICT/ADDRESS:
James M. Cantwell	4th Plymouth
Barbara L'Italien	Second Essex and Middlesex
Tom Sannicandro	7th Middlesex
Josh S. Cutler	6th Plymouth
Brian M. Ashe	2nd Hampden
Ruth B. Balser	12th Middlesex
Garrett J. Bradley	3rd Plymouth
Gailanne M. Cariddi	1st Berkshire
Michael S. Day	31st Middlesex
Tricia Farley-Bouvier	3rd Berkshire
Jennifer L. Flanagan	Worcester and Middlesex
Colleen M. Garry	36th Middlesex
Carlos Gonzalez	10th Hampden
Daniel J. Hunt	13th Suffolk
Jason M. Lewis	Fifth Middlesex
James J. O'Day	14th Worcester
Denise Provost	27th Middlesex
Ellen Story	3rd Hampshire

Walter F. Timilty	7th Norfolk
Jose F. Tosado	9th Hampden
Jonathan D. Zlotnik	2nd Worcester

HOUSE No. 3271

By Mr. Cantwell of Marshfield, a petition (accompanied by bill, House, No. 3271) of James M. Cantwell and others relative to nondiscrimination in access to organ transplants. Public Health.

The Commonwealth of Massachusetts

In the One Hundred and Eighty-Ninth General Court (2015-2016)

An Act concerning nondiscrimination in access to organ transplantation.

Whereas, The deferred operation of this act would tend to defeat its purpose, which is to provide forthwith for nondiscrimination in access to organ transplantation, therefore, it is hereby declared to be an emergency law, necessary for the immediate preservation of the public convenience.

Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:

- 1 SECTION 1. The General Court finds and declares that:
- 2 (1) a mental or physical disability does not diminish a person's right to health care;
- 3 (2) the "Americans with Disabilities Act of 1990" prohibits discrimination against
- 4 persons with disabilities, yet many individuals with disabilities still experience discrimination in
- 5 accessing critical
- 6 health care services;
- 7 (3) individuals with mental and physical disabilities have historically been denied life-
- 8 saving organ transplants based on assumptions that their lives are less worthy, that they are

- 9 incapable of complying with post-transplant medical regimens, or that they lack adequate
 10 support systems to ensure such compliance;
- (4) although organ transplant centers must consider medical and psychosocial criteria
 when determining if a patient is suitable to receive an organ transplant, transplant centers that
 participate in Medicare, Medicaid, and other federal funding programs are required to use patient
 selection criteria that result in a fair and nondiscriminatory distribution of organs; and
- 15 (5) Massachusetts residents in need of organ transplants are entitled to assurances that 16 they will not encounter discrimination on the basis of a disability.
- SECTION 2. Section 2 of chapter 113A of the General Laws, as appearing in the 2012

 Official Edition, is hereby amended by inserting after the definition of "Anatomical gift", the following 2 definitions:-
- "Auxiliary aids and services", qualified interpreters or other effective methods of making aurally delivered materials available to individuals with hearing impairments; qualified readers, taped texts, or other effective methods of making visually delivered materials available to individuals with visual impairments; provision of information in a format that is accessible for individuals with cognitive, neurological, developmental, or intellectual disabilities; provision of supported decision making services; acquisition or modification of equipment or devices; and other similar services and actions.
- "Covered entity", any licensed provider of health care services, including licensed health care practitioners, hospitals, nursing facilities, laboratories, intermediate care facilities, psychiatric residential treatment facilities, institutions for individuals with intellectual or

- developmental disabilities, and prison health centers; or any entity responsible for matching
- 31 anatomical gift donors to potential recipients.
- 32 SECTION 3. Said section 2 of said chapter 113A, as so appearing, is hereby further
- 33 amended by inserting after the definition "Decedent" the following definition:-
- 34 "Disability", as defined in the Americans with Disabilities Act Americans with
- 35 Disabilities Act of 1990, as amended by the ADA Amendments Act of 2008, at 42 U.S.C. §
- 36 12102.
- 37 SECTION 4. Said section 2 of said chapter 113A, as so appearing, is hereby further
- 38 amended by inserting after the definition "Organ procurement organization" the following
- 39 definition:-
- 40 "Organ transplant", the transplantation or transfusion of a part of a human body into the
- 41 body of another for the purpose of treating or curing a medical condition.
- 42 SECTION 5. Said section 2 of said chapter 113A, as so appearing, is hereby further
- 43 amended by inserting after the definition of "Prospective donor", the following 2 definitions:-
- "Qualified individual", an individual who, with or without the support networks available
- 45 to them, provision of auxiliary aids and services, or reasonable modifications to policies or
- 46 practices, meets the essential eligibility requirements for the receipt of an anatomical gift.
- 47 "Reasonable modification" or "reasonable modifications to policies or practices", may
- 48 include, but not be limited to: (i) communication with individuals responsible for supporting an
- 49 individual with post-surgical and post-transplantation care, including medication; (ii)
- 50 consideration of support networks available to the individual, including family, friends, and

- 51 home and community-based services, including home and community-based services funded
- 52 through Medicaid, Medicare, another health plan in which the individual is enrolled, or any
- 53 program or source of funding available to the individual, in determining whether the individual is
- 54 able to comply with post-transplant medical requirements.
- 55 SECTION 6. Said section 2 of said chapter 113A, as so appearing, is hereby further
- 56 amended by inserting after the definition of "State", the following definition:-
- 57 "Supported decision making", the use of a support person to assist an individual in
- 58 making medical decisions, communicate information to the individual, or ascertain an
- 59 individual's wishes, including: (i) inclusion of the individual's attorney-in-fact, health care
- 60 proxy, or any person of the individual's choice in communications about the individual's medical
- 61 care; (ii) permitting the individual to a person of their choice for the purposes of supporting that
- 62 individual in communicating, processing information, or making medical decisions; (iii)
- 63 provision of auxiliary aids and services to facilitate the individual's
- ability to communicate and process health-related information, including use of assistive
- 65 communication technology; (iv) provision of information to persons designated by the
- 66 individual,
- 67 consistent with the provisions of the Health Insurance Portability and Accountability Act
- of 1996, 42 U.S.C. § 1301 et seq., and other applicable laws and regulations governing
- 69 disclosure of health
- information; (v) provision of health information in a format that is readily understandable
- 71 by the individual; and (vi) the individual has a court-appointed guardian or other individual
- 72 responsible for making medical decisions on behalf of the individual, any measures to ensure

- that the individual is included in decisions involving his or her own health care and that medical decisions are in accordance with the individual's own expressed interests.
- 75 SECTION 7. Said chapter 113A is hereby further amended by adding the following 2 76 sections:-
- Section 26. (a) A covered entity shall not, solely on the basis of a qualified individual's mental or physical disability:
- 79 (1) deem an individual ineligible to receive an anatomical gift or organ transplant;
- 80 (2) deny medical and related services related to organ transplantation, including 81 evaluation, surgery, counseling, post-operative treatment and services;
- 82 (3) refuse to refer the individual to a transplant center or other related specialist for the 83 purpose of evaluation or receipt of an organ transplant;
- (4) refuse to place an individual on an organ transplant waiting list, or placement of the individual at a lower-priority position on the list than the position at which he or she would have been placed if not for his or her disability; or
- 87 (5) decline insurance coverage for any procedure associated with the receipt of the 88 anatomical gift, including post-transplantation care.

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90 (b) Notwithstanding subsection (a), a covered entity may take an individual's disability 91 into account when making treatment or coverage recommendations or decisions, solely to the 92 extent that the physical or mental disability has been found by a physician or surgeon, following

- an individualized evaluation of the potential recipient, to be medically significant to theprovision of the anatomical gift.
- This section shall not be deemed to require referrals or recommendations for, or the performance of, medically inappropriate organ transplants.
- 97 (c) If an individual has the necessary support system to assist the individual in complying
 98 with post-transplant medical requirements, an individual's inability to independently comply
 99 with those requirements shall not be deemed to be medically significant for the purposes of
 100 subsection (b).
- (d) A covered entity shall make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to make services such as transplantation-related counseling, information, coverage, or treatment available to qualified individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such services.
- (e) A covered entity shall take such steps as may be necessary to ensure that no qualified individual with a disability is denied services such as transplantation-related counseling, information, coverage, or treatment because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the services being offered or would result in an undue burden.
- (f) A covered entity shall otherwise comply with the requirements of Titles II and III of the Americans with Disabilities Act and ADA Amendments Act of 2008.
- (g) This section shall apply to each part of the organ transplant process.

Section 27. The remedy for violations of section 26 shall be the same as those available under Titles III and III of the Americans with Disabilities Act, 42 U.S.C. §§ 12131-12189. The court shall accord priority on its calendar and expeditiously proceed with an action brought to seek any remedy authorized by law for purposes of enforcing compliance with said section 26.