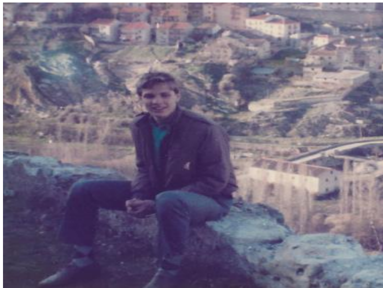
Brain Death
Clinician Duties when Families Object

Center For Bioethics & Medical Humanities
Medical College of Wisconsin ● June 2, 2015

Thaddeus Mason Pope, J.D., Ph.D.
Hamline University Health Law Institute

1985



Roadmap

6 parts

1. Legal **status** of brain death

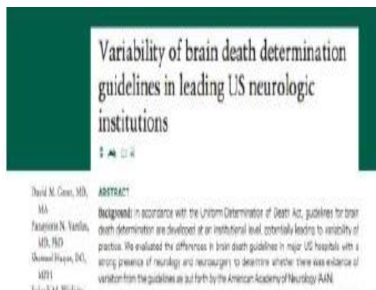
2. **Non**-religious objections to BD
3. How to **respond**

4. **Religious** objections to brain death
5. Duties to **accommodate**

6. Reasons to **extend** duties to accommodate

Part 1 of 6

Legal status of brain death



All 56 US jurisdictions

(narrow exception in NJ)

UDDA

An individual . . . . . **is dead** . . .
who has sustained ***either***

(1) irreversible cessation of circulatory and respiratory functions, ***or***

(2) irreversible cessation of all functions of the entire brain

total brain failure = death

20 years

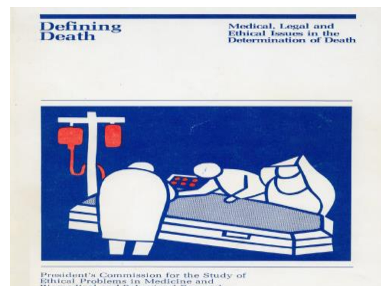
JAMA, Aug 5, 1968 • Vol 205, No 6

A Definition of Irreversible Coma

Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death

If this position is adopted by the medical community, it can form the basis for change in the current legal concept of death. No statutory change in the law should be necessary since the law treats this question essentially as one of fact to be determined by physicians.

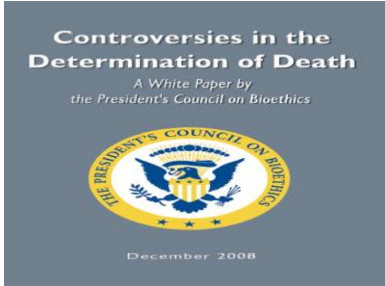
Wrong



UDDA

Legally **settled** since 1980s

Remains settled (legally)



"durable worldwide consensus"

Bernat 2013

Clinician duties after death

Annals of Internal Medicine

American College of Physicians Ethics Manual

Sixth Edition

Lois Snyder, JD, for the American College of Physicians Ethics, Professionalism, and Human Rights Committee*

"After a patient . . . brain dead . . . medical support should be **discontinued**."

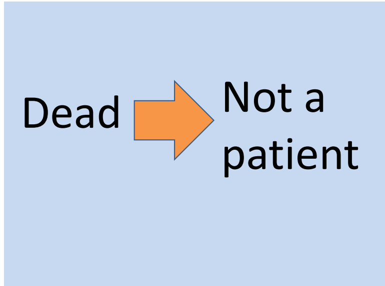
Guidelines for Physicians: Forgoing Life-Sustaining Treatment for Adult Patients

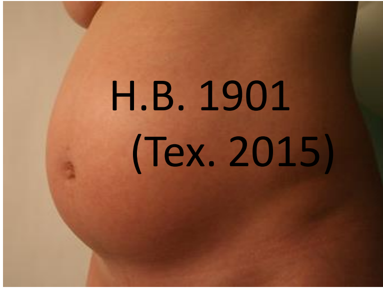
Joint Committee on Biomedical Ethics of the Los Angeles County Medical Association and Los Angeles County Bar Association

Approved by the Los Angeles County Medical Association February 15, 2006
Approved by the Los Angeles County Bar Association March 22, 2006

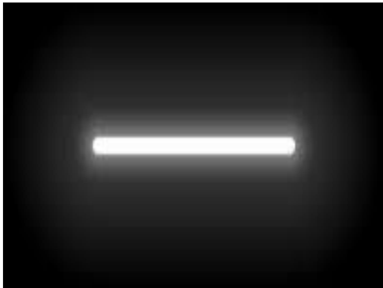
"Once death has been pronounced, all medical interventions should be withdrawn."

Consent **not** required to stop physiological support





Not a patient → No duty to treat



BUT

13 ethics consults "because family members asked clinical caregivers to deviate from standard procedures following brain death"

AL Flamm et al, "Family members' requests to extend physiologic support after declaration of brain death: a case series analysis and proposed guidelines for clinical management," J Clin Ethics (2014) 25(3):222-37.

"in recent months . . . the families of two patients determined to be dead by neurologic criteria have rejected this diagnosis"

JM Luce, "The Uncommon Case of Jahi McMath," Chest (2015) 147(4):1144-51.

Non-religious

Religious

Part 2 of 6

Non-religious objections

Diagnostic confusion

Prognostic mistrust

Diagnostic confusion

"Since there is a **heartbeat** (and he is **warm**), he is alive."

"He's in a **coma**."

"With rehab/time he'll get better."

Miracles

If the doctors treating your family member said futility had been reached, would you believe that divine intervention by God could save your family member?

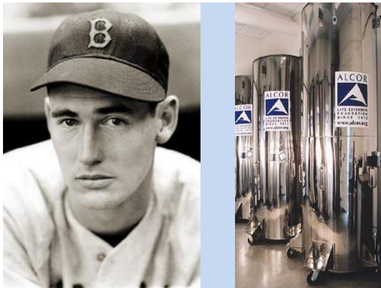
Yes	57.4

Trauma Death

Views of the Public and Trauma Professionals on Death and Dying From Injuries

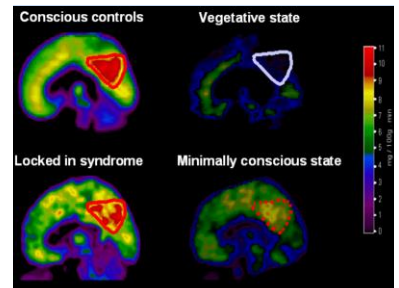
Lenworth M. Jacobs, MD, MPH; Karyl Burns, RN, PhD; Barbara Bennett Jacobs, RN, MPH, PhD, CHPN

Arch Surg. 2008;143(8):730-735



Linguistic Confusion

"Brain dead" implies not **really** "dead"



Brain-Dead Canadian Woman Dies After Giving Birth to Boy

The New York Times
Friday, February 23, 2007

Health

WORLD | U.S. | N.Y. / REGION | BUSINESS | TECHNOLOGY | SCIENCE | HEALTH | SPORTS

FITNESS & NUTRITION | HEALTH CARE POLICY

Brain-Dead Florida Girl Will Be Sent Home on Life Support

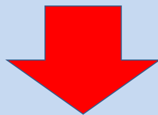
Published: February 19, 1994

"she is **'brain dead' and** . . . being **kept alive** by life support to enable the family to say their goodbyes."

Daily Mail, 03-18-09

Prognostic Mistrust

wrong before



wrong now

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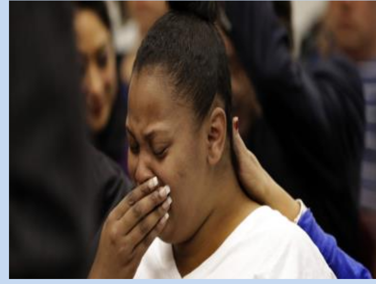
6
7
8 SUPERIOR COURT OF THE STATE OF CALIFORNIA
9 FOR THE COUNTY OF ALAMEDA
10
11
12 LATASHA NAILAH SPEARS WINKFIELD; MARVIN WINKFIELD; SANDRA CHATMAN;
13 and JAHI McMATH, a minor, by and through her Guardian Ad Litem,
14 LATASHA NAILAH SPEARS WINKFIELD,

COMPLAINT FOR DAMAGES FOR MEDICAL MALPRACTICE



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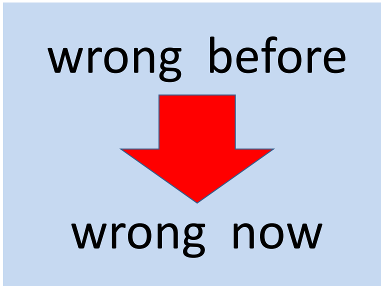
ELECTRONICALLY FILED
Superior Court of California, County of Orange
02/27/2015

SUPERIOR COURT OF THE STATE OF CALIFORNIA
FOR THE COUNTY OF ORANGE

LISA AVILLA, ROBERTO CHAVEZ,
Plaintiffs,
vs.
AHMC ANAHEIM REGIONAL MEDICAL CENTER, L.P., a Partnership, doing business as AHMC ANAHEIM REGIONAL MEDICAL CENTER; AHMC HEALTHCARE INC., a California Corporation; FREDERICK DIETERICH, M.D.; FREDERICK W. DIETERICH, M.D., A PROFESSIONAL CORPORATION, a California Corporation; BANSARI SHAH, M.D; BANSARI SHAW, MD

Case No. 30-2015-00774798-CU-MM-CXC
Judge Thierry Colaw
COMPLAINT FOR DAMAGES FOR MEDICAL MALPRACTICE
1. Negligence
2. Loss of Consortium



Clinicians were correct

But many other times, **wrong**

Arizona College Student Bounces Back From the Dead After Nearly Giving Organs

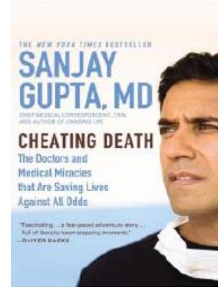
Alvarado

- Sept. 15, 1989 DDNC
- Sept. 21 social worker
- Sept. 22 parents file
- Oct 13 independent expert
- Oct 18 order
- Appeal dismissed (not dead)

Los Angeles Times

Close call in death ruling of potential organ donor (April 12, 2007)

John Foster at Fresno Community



They were declared **brain dead**. It was written in their chart as such. And here they are, sitting up talking to me.

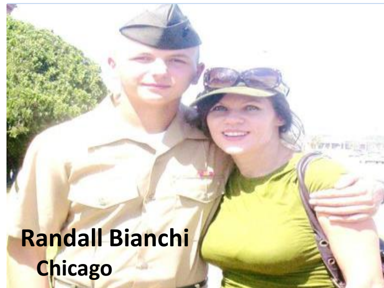
Negligent errors

More culpable errors

Hootan Roozrokh

$1.2 million settlement in 'organ harvest' case

November 19, 2012 12:00 AM


Randall Bianchi
Chicago

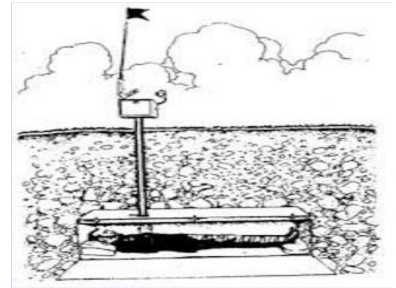
Non-religious objections

Diagnostic confusion

Prognostic mistrust

Exacerbating factors (3)

Taphophobia



Maria de Jesus Arroyo

Taphophobia:
people want
to be **sure**

Variability

Brain death
concept
accepted across
USA & world

Irreversible cessation of all brain function including the brain stem

How is irreversible cessation **measured**?

Legal variation
- # physicians
- Qualifications
- How tests performed

"acceptable medical standards"

"ordinary standards"

"usual & customary standards"

Variability of brain death determination guidelines in leading US neurologic institutions

David M. Greer, MD, MA
Panayiotis N. Varelas, MD, PhD
Shamael Haque, DO, MPH
Eelco F.M. Wijdicks, MD, PhD

ABSTRACT

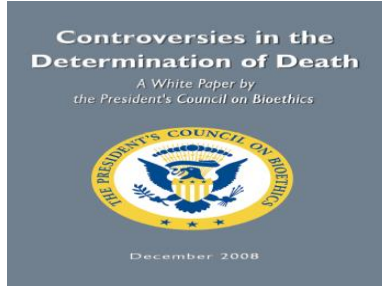
Background: In accordance with the Uniform Determination of Death Act, guidelines for brain death determination are developed at an institutional level, potentially leading to variability of practice. We evaluated the differences in brain death guidelines in major US hospitals with a strong presence of neurology and neurosurgery to determine whether there was evidence of variation from the guidelines as put forth by the American Academy of Neurology (AAN).

Methods: We requested the guidelines for determination of death by brain criteria from the US News and World Report top 50 neurology/neurosurgery institutions in 2006. We evaluated the guidelines for five categories of data: guideline performance, preclinical testing, clinical examination, apnea testing, and ancillary tests. We compared the guidelines directly with the AAN guidelines for consistencies/differences.

Results: There was an 82% response rate to requests. Major discrepancies were present among institutions for all five categories. Variability existed in the guidelines' requirements for performance of the evaluation, prerequisites prior to testing, specifics of the brainstem examination and apnea testing, and what types of ancillary tests could be performed, including what pitfalls or limitations might exist.

Conclusions: Major differences exist in brain death guidelines among the leading neurologic hospitals in the United States. Adherence to the American Academy of Neurology guidelines is variable. If the guidelines reflect actual practice at each institution, there are substantial differences in practice which may have consequences for the determination of death and initiation of transplant procedures. Neurology® 2008;70:284–289

Conceptual Incoherence



Heal wounds
Fight infections
Gestate fetus
Stress response

FROM THE MAY 2012 ISSUE

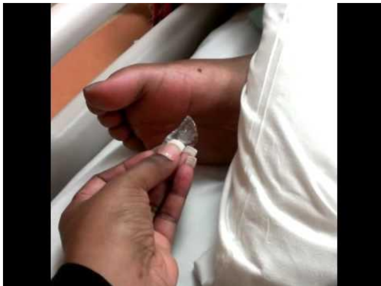
The Beating Heart Donors

They urinate. They have heart attacks and bedsores. They have babies. They may even feel pain. Meet the organ donors who are "pretty dead."

By Dick Teresi | Wednesday, May 02, 2012

RELATED TAGS: ORGAN TRANSPLANTS, SENSES

UMN, *J Neurosurgery* 35(2): 211-18
Brain dead subjects sexually responsive



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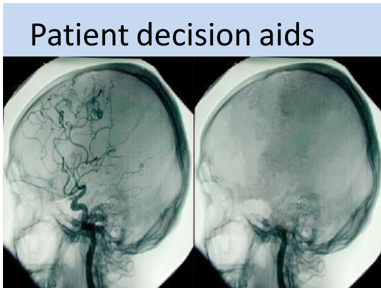
9 IN AND FOR THE COUNTY OF ALAMEDA
10 UNLIMITED CIVIL JURISDICTION
11
12 LATASHA WINKFIELD, | Case No.: PR13-707598
13 Plaintiff, | WRIT OF ERROR CORUM NOBIS AND MEMORANDUM REGARDING COURT'S JURISDICTION TO HEAR PETITION FOR DETERMINATION THAT JAHI MCMATH IS NOT BRAIN DEAD
14
15 v.
16 CHILDREN'S HOSPITAL, et al.
17 Defendants.
18

Dr. Paul Byrne

Part 3 of 6

Responses

Diagnostic confusion



JAMA PATIENT PAGE The Journal of the American Medical Association

BRAIN FUNCTION

Brain Death

A person dies when brain function ceases, the heart stops beating, and breathing and blood circulation cease. Because life-support techniques have become so advanced, it is possible that even in the face of fatal injury or unrecoverable illness, the heart can be kept beating with medication, and **respiration** (breathing) can be artificially performed with a ventilator. The concept of brain death developed in response to these advanced medical techniques that can maintain some bodily functions. **Brain death**, as understood in US law and medical practice, occurs when there is no function of the entire brain. The **brainstem** is the area of the brain that controls breathing and circulation and therefore controls essential life functions. When the brain, including the brainstem, has ceased to function, the individual is truly dead by medical and legal standards. Thus, brain death is real death. The March 18, 2009, issue of *JAMA* includes an article about brain death. This Patient Page is based on one published in the May 14, 2008, issue of *JAMA*.

PLANE OF CROSS SECTION

CROSS SECTION

Cerebrum

Cerebellum

Brainstem

CLINICAL CRITERIA FOR BRAIN DEATH

- No response to any stimulus—no movement, withdrawal, grimace, or blinking
- No breathing efforts when taken off the ventilator (the **apnea test**)
- Pupils dilated and not responsive to light
- No gag reflex, no **corneal reflex** (blinking when the surface of the eye is touched), and absence of other specific reflexes

TESTING

- Computed tomography (CT) scans of the brain may show abnormalities such as bleeding (**hemorrhage**), massive stroke, brain injury, or severe brain swelling (**edema**).
- **Electroencephalography** (EEG) records electrical brain activity. If brain death is present, the EEG will show no activity

FOR MORE INFORMATION

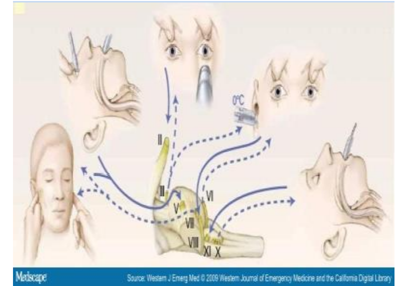
- National Institute of Neurological Disorders and Stroke www.ninds.nih.gov
- American Academy of Neurology www.aan.com
- United Network for Organ Sharing www.unos.org

INFORM YOURSELF

To find this and previous JAMA

Do **not** use the term "brain death"

Mistrust



Tawil I et al, "Family presence during brain death evaluation: a randomized controlled trial" - Crit Care Med. 2014 Apr;42(4):934-42

Independent second opinion

But we've got to verify it legally, to see if she is morally, ethically spiritually, physically positively, absolutely undeniably and reliably Dead

And she's not only **merely** dead,

she's really most **sincerely** dead.

Paul Fisher

Stanford Child Neurology

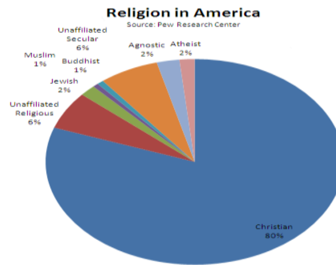
Non-religious objections

Part 4 of 6

Religious objections

total brain failure ≠ death

Not dead until heart or breathing stops



Orthodox Jews

Japanese Shinto

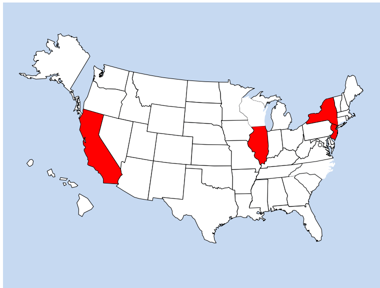
Native Americans

Buddhists

Muslim (some)

Part 5 of 6

Duties to accommodate objections



CA IL NY

1986

2007

2008

"Each hospital shall establish . . . procedure for the **reasonable accommodation** of the individual's religious . . . objection. . . ."

10 N.Y.C.R.R. § 400.16(e)(3)

Dead → No duty treat

Dead → No duty treat

NY CA IL change this

Imposes duties to “treat” **after** DDNC

Limited

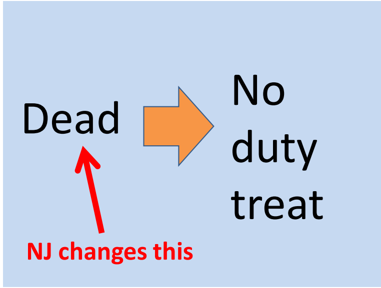
“reasonably brief period”

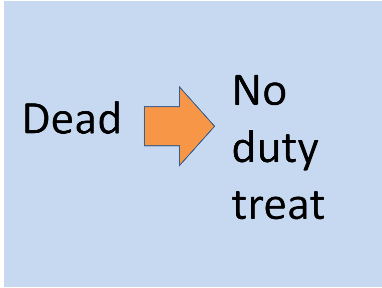
“amount of time afforded to gather family or next of kin at the patient's bedside”

<24 x x x x
24 x x x x x x
36
48 x
72 x x x

NJ

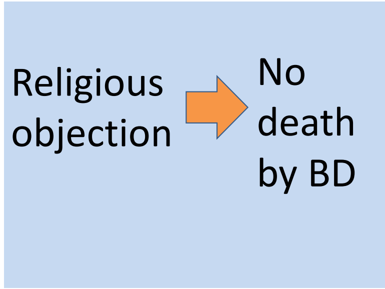
Opposite

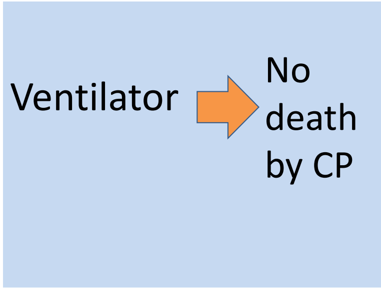




Changes definition **itself**

"[D]eath . . . **shall not be declared** upon the basis of neurological criteria . . . when . . . violate the **personal religious beliefs** . . . ."





Indefinite accommodation

Until death by CP criteria

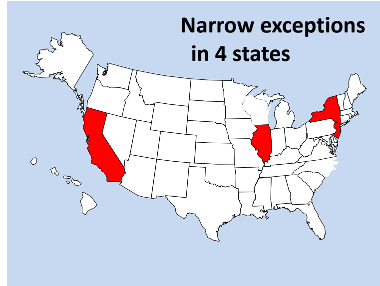
Shewmon

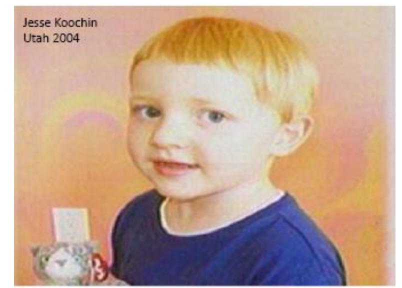
80% < 4 weeks

20% > 4 weeks

10% > 8 weeks

5% > 6 months

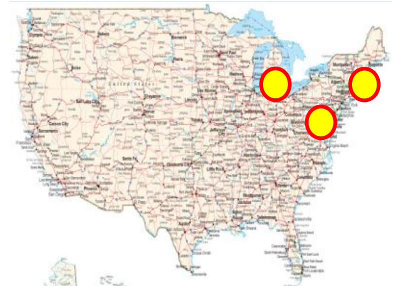


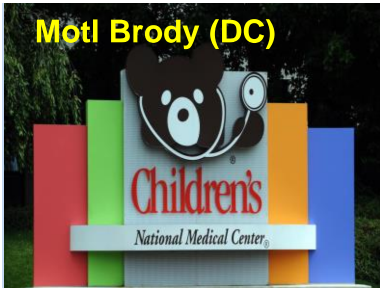


Other transfers

Girl (CA)
Hamilton (FL)
Scoon (NY)
Shively (KS)

Accommodation denied elsewhere





Part 6 of 6

Extend duties to accommodate

4 reasons

1. BD **imposes** on profound beliefs

Minn. S.F. 1694

no autopsy when religious objection unless compelling state interests

2. Accommodation has **worked** for decades in 4 populous states

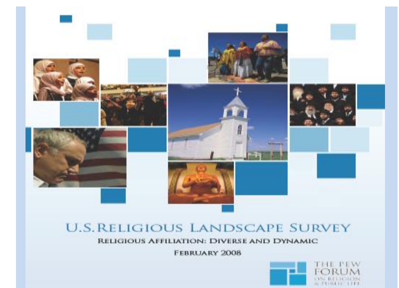
3. Duties are **limited**

Frequency

Brain death

< 1%

hospital deaths



0.3	Japanese Shinto
0.3	Orthodox Jew
0.3	Native American
0.7	Buddhist

2% of 1% = 0.0002

1 in 5000 deaths

400 cases nationwide annually

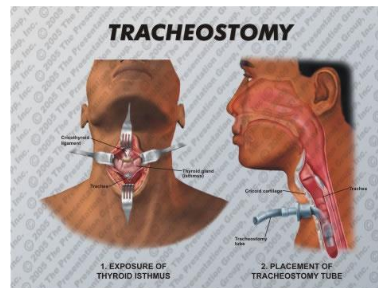
Most in

CA, NY, IL, NJ

Type

“hospital is required to continue **only** previously ordered cardiopulmonary support. No other medical intervention is required.”

18. Plaintiffs are Christians with firm religious beliefs that as long as the heart is beating, Jahi is alive. Plaintiff Winkfield has personal knowledge of other who had been diagnosed as brain dead, where the decision makers were encouraged to “pull the plug” yet they didn’t and their loved one emerged from legal brain death to where they had cognitive ability and some even fully recovering. These religious beliefs involve providing all treatment, care, and nutrition to a body



Duration

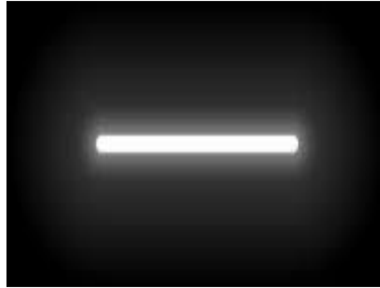
24 h

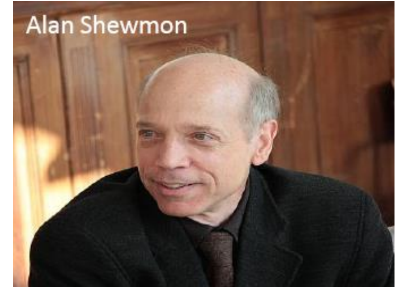
205

“in determining what is reasonable, a hospital shall consider . . . **needs of other patients** . . . .”

4. Brain death conceptually flawed

total brain failure = Death





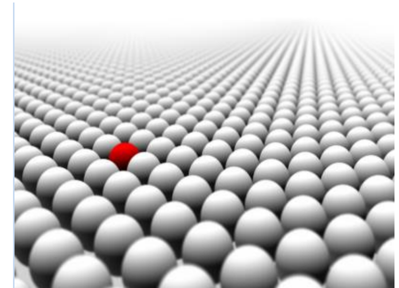
Value laden judgment about when it is **worthwhile** to continue physiological support

AMERICAN THORACIC SOCIETY DOCUMENTS

An Official American Thoracic Society Policy Statement: Managing Conscientious Objections in Intensive Care Medicine

Mithya Lewis-Newby, Mark Wicclair, Thaddeus Pope, Cynda Rushton, Farr Curlin, Douglas Diekema, Debbie Durrer, William Ehlenbach, Wanda Gibson-Scipio, Bradford Glavan, Rabbi Levi Langer, Constantine Manthous, Cecile Rose, Anthony Scardella, Hasan Shanawani, Mark D. Siegel, Scott D. Halpern, Robert D. Truog, and Douglas B. White; on behalf of the ATS Ethics and Conflict of Interest Committee

This official Policy Statement of the American Thoracic Society (ATS) was approved by the ATS Board of Directors, October 2014



Only NJ **changes** who is dead

CA – IL – NY accommodation does **not** threaten uniformity

"practically oriented bioethicist"

Veatch, J Med Phil (2015) 40:289-311

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B medicalfutility.blogspot.com

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References

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Medical Futility Blog

Since July 2007, I have been blogging, almost daily, to **medicalfutility.blogspot.com**. This blog is focused on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning medical futility and end-of-life medical treatment conflict. The blog has received over 850,000 direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like Westlaw, Bioethics.net, Wellsphere, and Medpedia.

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