

**Brain Death
Hard Cases &
Legal Challenges**

Harvard Medical School Annual Bioethics
Conference • April 12, 2018

Thaddeus Mason Pope, JD, PhD

UDDA

Alex Capron

“well
settled”

Less

well settled

Roadmap

2 parts

Part **1**

Resistance
to BD is
growing

Part **2**

5 legal attacks on BD

Least
↓
Most serious

Growing resistance

More families dispute BD

CONTEMPORARY ISSUES

Organ support after death by neurologic criteria
Results of a survey of US neurologists (200)

NEUROLOGY
Aug. 2016

Ariane Lewis, MD
Nelle Adams, BA
Pamela Vardi, MD
BD
David Geer, MD, MA
Arthur Caplan, PhD

50% report families request organ support **after** BD



“families of . . . patients determined . . . dead by neurologic criteria . . . **rejected this diagnosis**”

Chest (2015) 147(4):1144-51



“family . . . asked . . . to **deviate** from standard procedures following BD”



Conflict: **10%**

56 BD cases
2014-2016

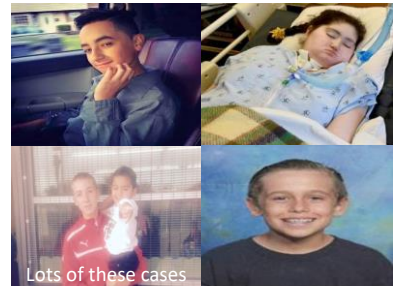
More
conflict

Many cases
to **court**


5 Types of
dispute

Attack
1 of 5

Confusion
Mistrust

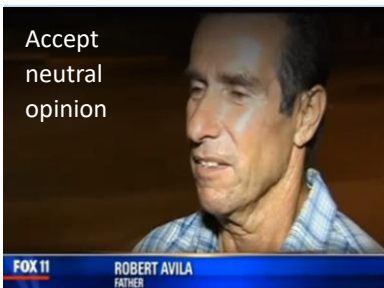


Just 1
example

SUPERIOR COURT OF CALIFORNIA
OF CALIFORNIA
COUNTY OF ORANGE

Injunction against
removing ventilator



That's
1st attack
on BD

Attack 2 of 5

Want
religious
exemption



“[D]eath . . . shall not be declared . . . neurological criteria . . . violate . . . **personal religious beliefs**”

Religious objection → No death by BD

Contrast
CA, NY, IL

Dead → **Temp** duty “treat”

24-48hr

Reasonable accommodation **after** BD

NJ

Opposite

Changes
definition
itself

Pt may
satisfy
BD criteria

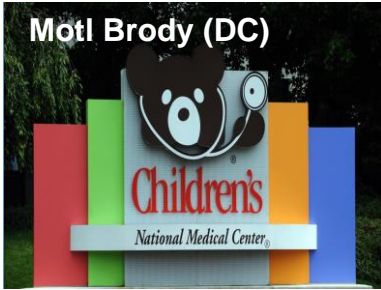
BUT

May **not**
declare
death

Until
death by
CP criteria

Exemption
Not mere
accommodation

Rejected
everywhere
outside NJ



California
rejected
(twice)

AMENDED IN ASSEMBLY APRIL 10, 1986
CALIFORNIA LEGISLATURE—1985-86 REGULAR SESSION
ASSEMBLY BILL No. 3311

Introduced by Assembly Member **Hill Katz**

February 18, 1986

An act to amend Section 14122 of the Welfare and Institutions Code, relating to MediCal. An act to amend Section 7180 of the Health and Safety Code, relating to The Uniform Determination of Death Act.

LEGISLATIVE COUNSEL'S DIGEST
AB 3311, as amended, **Hill Katz**. MediCal covered benefits The Uniform Determination of Death Act.

AMENDED IN ASSEMBLY APRIL 6, 1987
CALIFORNIA LEGISLATURE—1987-88 REGULAR SESSION
ASSEMBLY BILL No. 1390

Introduced by Assembly Member **Katz**

March 4, 1987

An act to add Section 1256.5 to the Health and Safety Code, relating to health facilities.

LEGISLATIVE COUNSEL'S DIGEST
AB 1390, as amended, **Katz**. Health facilities: general acute care hospitals.

BUT

3 active cases

1



Shalom Ouanounou

BD guidelines “failed to . . . accommodate Shalom’s express **religious beliefs**, . . . violate . . . constitutional and human rights”

2



Taquisha McKitty



Apostolic Pentecostal

Submitted
Awaiting
decision

3



Case 2:16-cv-00889-KJM-EFB Document 64 Filed 07/03/16 Page 1 of 17

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 23
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 26
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 28

IN THE UNITED STATES DISTRICT COURT
 FOR THE EASTERN DISTRICT OF CALIFORNIA

17 Josee Fonseca, an individual parent } Case No.: 2:16-cv-00889-KJM-EFB
 18 and guardian of Israel Stinson, a }
 19 minor, } Second Amended Complaint for
 20 Plaintiff, } Equitable Relief
 21 v. }
 22 Karen Smith, M.D. in her official } REQUEST FOR JURY TRIAL
 23 capacity as Director of the California }
 24 Department of Public Health, and Doe }
 25 2 through 10, inclusive, }
 26 Defendant }

“Plaintiffs are Christians with firm **religious beliefs** . . . heart is beating, Israel is alive.”

“removal of CP support . . . **unconstitutional** . . . interferes with . . . freedom of religion . . . first amendment”



May see **more** of these cases



That’s **2nd** attack on BD

Attack
3 of 5

Must clinicians
obtain **consent**
for BD tests?

1968



JAMA, Aug 5, 1968 • Vol 205, No 6

A Definition of Irreversible Coma

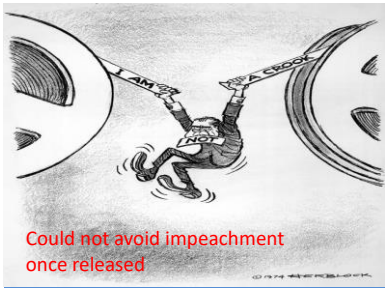
Report of the Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death



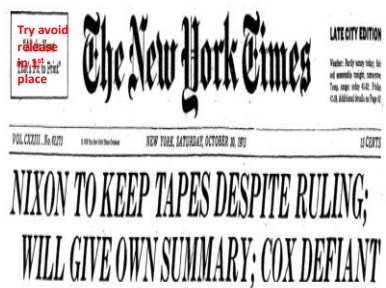
How is this relevant?



Watergate tapes were damning



Could not avoid impeachment once released



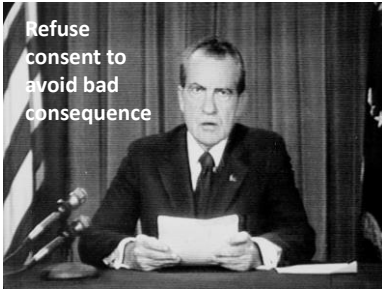
Try avoid release into public place

The New York Times

LATE CITY EDITION
Market: Each copy 15¢; 10¢ at newsstand; single copies 10¢; 5¢ per copy; 4¢; 3¢; 1¢ (U.S. Mail and Post Office)

POL. CRISIS, IN 4219 4 1/2 IN. BY 6 IN. NEW YORK, SATURDAY, OCTOBER 26, 1971 17 CENTS

NIXON TO KEEP TAPES DESPITE RULING; WILL GIVE OWN SUMMARY; COX DEFLIANT



Similarly

Some try to **prevent** BD diagnosis

Why?
this strategy

Clinician duties **after** BD

Limited

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.**”

CDMA
California Medical Association
Views & Reviews

Really, most SINCERELY dead
Policy and procedure in the diagnosis of death by neurologic criteria
D.M. Shaner, MD, R.D. Orr, MD, T. Drought, PhD, R.N. R.B. Miller, MD, and M. Siegel, MD

“once death . . . diagnosed . . . **discontinue** support . . .”

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

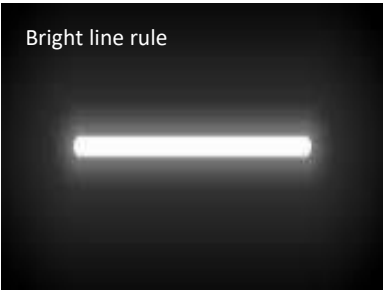
Approved by the Los Angeles County Medical Association February 15, 2006
Approved by the Los Angeles County Bar Association March 22, 2006

“all medical interventions should be **withdrawn.**”

Consent
not
required

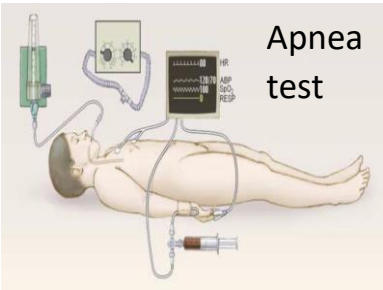
Dead → Not a
patient

Not a
patient → **No** Tx
duty

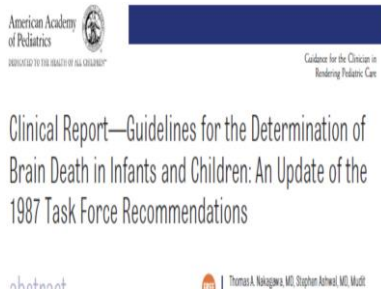
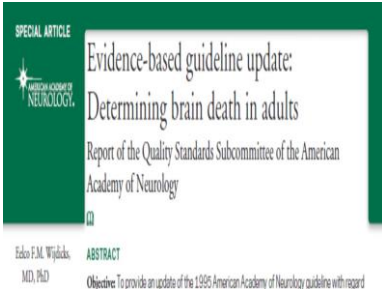


No **post**-BD
treatment rights

Focus on
pre-BD
rights



Final
confirmatory test



BUT

More family **refusals**



Parental refusals



No apnea test
 ↓
 No BD

No BD
 ↓
 Treatment duties continue until CP

Practically, same
as NJ religious
exemption

Opt out
BD

No apnea test →
ancillary tests

But **same**
consent
question

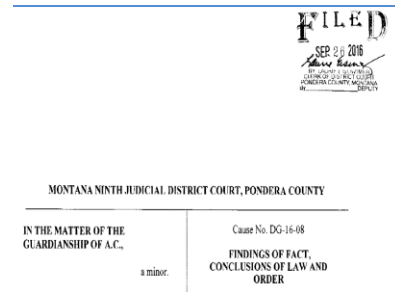
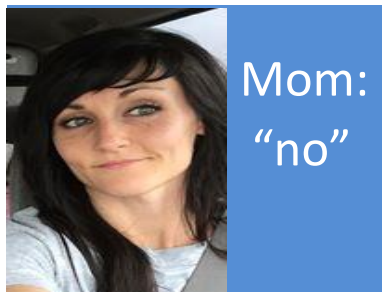
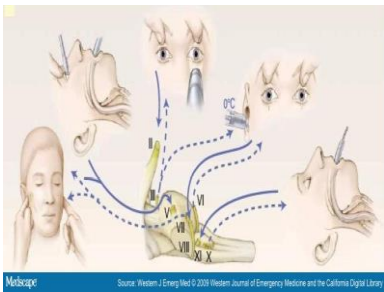
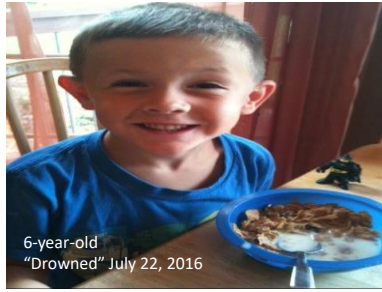
Must clinicians
honor the
refusal?

Do clinicians
need **consent**
for apnea test?



Yes

Allen
Callaway



"request . . .
permitting . . .
testing . . .
is denied"

"**mother has sole authority** to make medical decisions . . . including . . . brain functionality examinations"






Do clinicians need **consent** for apnea test?

MT said **“yes”**

KS also said **“yes”**

Forbid brain viability exam
TRO - 02/01/06
D/C home - 03/17/06

Do clinicians need **consent** for apnea test?

CA also said **“yes”**



1 ALLISON ARANDA
 2 P.O. Box 2014
 3 Santa Ana, CA 92759
 4 707.227.6744

5
 6 Attorney for Petitioner

7
 8 SUPERIOR COURT OF THE STATE OF CALIFORNIA
 9 FOR THE COUNTY OF SAN BERNARDINO

10
 11
 12
 13
 14 ALEX PIERCE, by and through his
 15 mother SABRINA PIERCE
 16 Plaintiff,

17 vs.
 18 LOMA LINDA UNIVERSITY MEDICAL
 19 CENTER,
 20 Defendant

FILED
 Superior Court of California
 County of San Bernardino
 JUN 7 2016
 BY *[Signature]* DEPUTY

Case No.: CIV-DS-1608931
 PROPOSED ORDER ON EX PARTE
 MOTION FOR TEMPORARY
 RESTRAINING ORDER



To the Drs of Israel E. Stinson
 I will be stepping away
 today but I will leave my
 contact number please do not
 hesitate to call me if anything
 happens with my son. In my
 absence Please DO NOT perform
 any tests or exams on Israel
 without my consent or presence.
 Thank you so much.
 Jones Fonseca (510) 575-5314
 P.S. I decline of any apnea
 test that may be performed
 on Israel Stinson. **Aug. 9, 2016**
 to CHLA

MT, KS, CA
said "yes"

Neurology
 Aug 2016
 87(8) 827-34

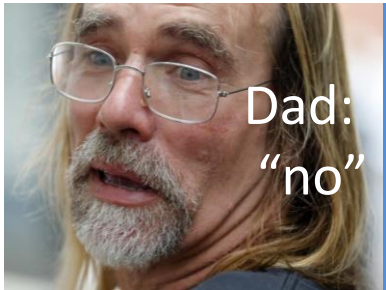
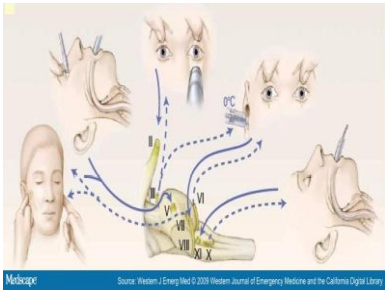
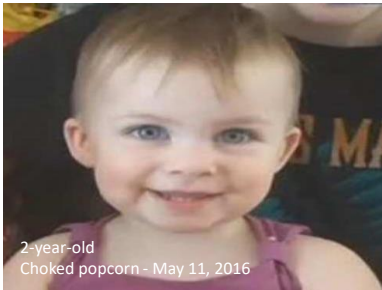
Organ support after death by neurologic
 criteria
 Results of a survey of US neurologists

1/4 neurologists
 say need consent

No



Mirranda Lawson



I Alison Lawson and Patrick Lawson refuse any sort of "Brain Dead" testing including the "Apnea" test on our daughter Mirranda Grace Lawson. We do not want the ventilator removed or cut-off for any amount of time. We are Christians and it is against our religious beliefs to remove the ventilator. Her heart is still beating. Removing life support will cause death. That is murder and is against the Christian faith.

Signed Alison Lawson Patrick Lawson
Witnessed Karen Roney Stacy
Witnessed Jan Rade Stacy



Hospital
"is . . . allowed
to administer
the apnea test"



Almost got first **appellate** guidance

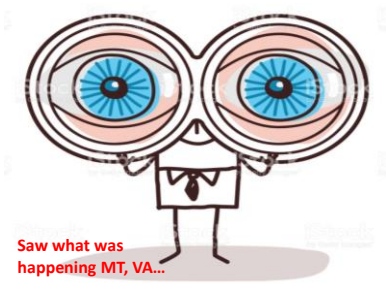
BUT



Do clinicians need **consent** for apnea test?

VA said **“no”**

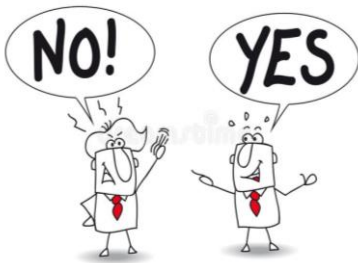
NV also said **“no”**



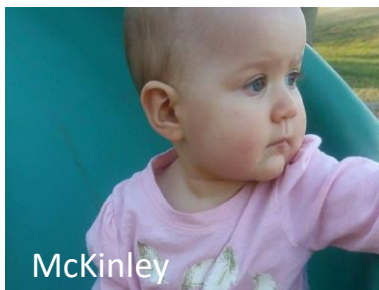


“determination of the death . . . is a clinical decision that does **not require the consent** of the person’s . . . representative . . .”

Do clinicians need **consent** for apnea test?



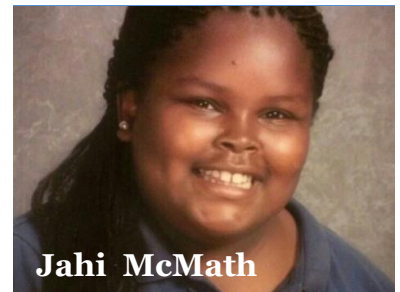
YES	NO
California	Nevada
Kansas	Virginia
Montana	



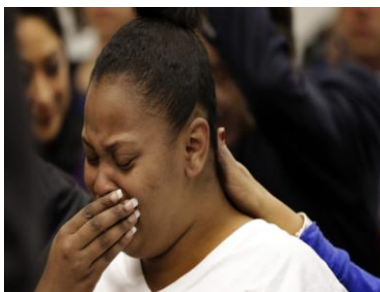


That's
3rd attack
 on BD

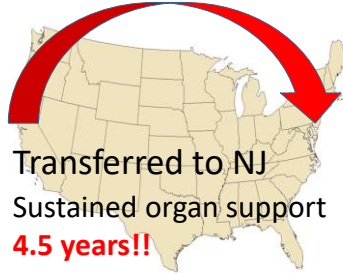
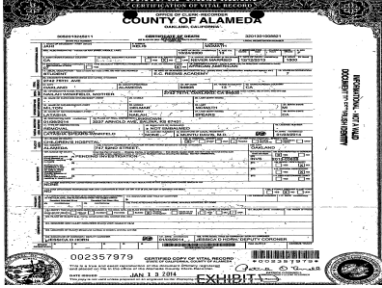
Attack
4 of 5



Dec. 12, 2013
 Declared dead



Lost lawsuits
 against
 hospital



Mar. 2015
Med Mal lawsuit


future
medical
expenses

Dead people
do **not** have
medical expenses

Re-litigate
status as
alive



Chance
to prove

 SUPERIOR COURT OF CALIFORNIA
COUNTY OF ALAMEDA
“Triable issue . . .
whether changed
circumstances”

2 theories

1

Does not attack
the AAN criteria
themselves



**No longer meets
AAN criteria**

AAN = UDDA

Jahi \neq AAN

Argument
over **facts**,
not law

If alive, must
reexamine
medical criteria
for BD

Dead at T1



Not dead at T2

Problem

Death
should be
irreversible

2

DECEMBER 2017						
SU	MO	TU	WE	TH	FR	SA
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30
31						

“most
likely **fail**
BD exam”

Attack not only
application
BD exam to Jahi

Attack
legitimacy
exam **itself**

Jahi = AAN
AAN **≠** UDDA

That's **5th**
challenge

Attack
5 of 5

Most
serious
attack

Are medical
criteria for BD
legally
sufficient?



April 1, 2015
Catastrophic anoxic
brain injury during
exploratory
laparotomy

May 28, 2015
Met AAN criteria
for brain death



Dad
loses

Trial court

AAN criteria met
Aden **is** dead



Dad wins



Irrelevant if Aden
meets AAN criteria
They are **not** the
“right” criteria

2 reasons

1

AAN does **not**
measure what
the **UDDA**
requires

UDDA

“irreversible
cessation . . .
all functions of
. . . **entire** brain”

BUT

Brain dead
people
do stuff



AAN measures
only cessation
some functions
of **part** of brain

Supposed to
measure:
“**all** functions”
“**entire** brain”

2

UDDA

“must be made in accordance with **accepted medical standards**”

BUT

Research

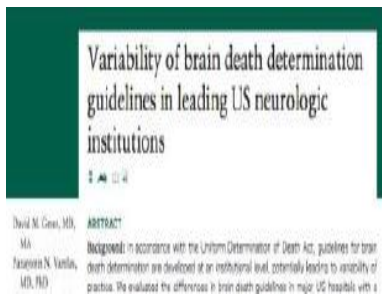
Original Investigation

Variability of Brain Death Policies in the United States

David M. Green, MD, MA, Hilary H. Wang, BA, Jennifer D. Robinson, APRN, Paragotis N. Varelas, MD, PhD, Gaber V. Henderson, MD, Edco F. M. Wijicks, MD, PhD

IMPORTANCE Brain death is the irreversible cessation of function of the entire brain, and it is a medically and legally accepted mechanism of death in the United States and worldwide.

Supplemental content at jamaneurology.com



Number of physicians
Qualifications
How tests administered

Hailu = AAN
AAN **≠** UDDA

SCT did **not** hold

Remand for evidentiary hearing

BUT



Court
throws BD
into **doubt**

But no
resolution



Nevada
legislature
steps in



BUT

Addressed only
1 of 2 problems
identified by
supreme court

1

“accepted
medical
standards”

AAN / AAP
authoritative
criteria

2

Legal standard
may demand
more than
medical criteria



What is
issue?

UDDA

“**irreversible**
cessation . . .
all functions of
. . . **entire** brain”

Deferred to
medical
profession **how**
to measure

ULC


“Act is **silent** on acceptable diagnostic tests and medical procedures”

“medical profession **remains free** to formulate acceptable medical practices”



Tests & procedures must determine satisfaction of the **legal standard**

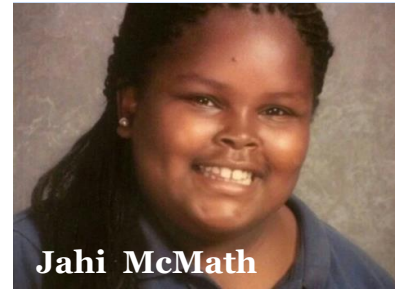


Medically dead
 
 Legally dead

think Legally dead
 
 Withdraw OST

actually Withdraw OST

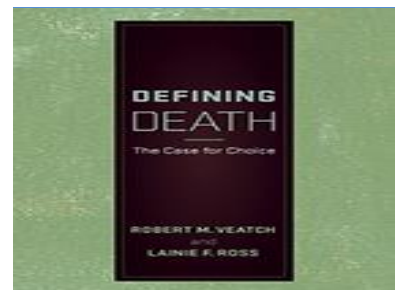
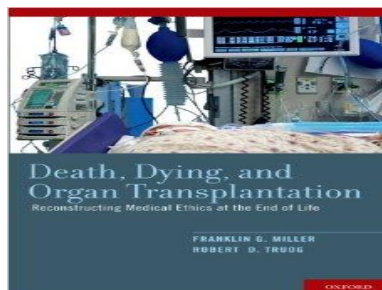
 Legally dead

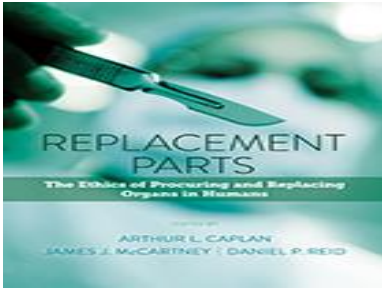


Conclusion

5 legal attacks on BD

Debate has been academic





“critics and skeptics have **not** gained much traction with lawmakers”

Not true anymore



Now it is a public policy question

Not just more scrutiny more debate

Reassess settled laws & practices

References

Materials from the cases discussed in this presentation are available at <http://thaddeuspope.com/braindeath>

Medical Futility Blog

Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com. This blog focuses on reporting and discussing legislative, judicial, regulatory, medical, and other developments concerning medical futility and end-of-life medical treatment conflicts. The blog has received over **3 million** direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like WestlawNext and Bioethics.net.

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Brain Death Rejected: Expanding Clinicians' Legal Duties to Accommodate Religious Objections and Continue Physiological Support, in *LAW, RELIGION, AND AMERICAN HEALTHCARE* (Cambridge Univ. Press 2017).

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Legal Briefing: Brain Death and Total Brain Failure, 25(3) *JOURNAL OF CLINICAL ETHICS* 245-257 (2014).

Pregnant and Dead in Texas: A Bad Law, Badly Interpreted, *LOS ANGELES TIMES* (Jan. 16. 2014) (with Art Caplan).

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