

**Brain Death  
Bioethics**  
Fundamental Principles  
& Emerging Issues

Thaddeus Mason Pope, JD, PhD  
Eighth Annual Great Lakes  
Palliative Care Conference  
Lake Geneva WI • May 3, 2019

1

Nothing  
to disclose

2



3



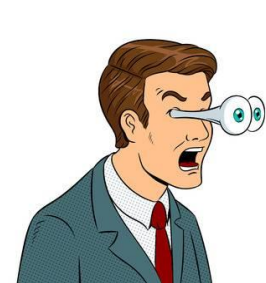
4



5

“Restoration of  
brain circulation  
and cellular  
functions hours  
post-mortem”

6



7

Scientists Restore  
Some Brain Function  
**After** Death

**THE WALL STREET JOURNAL.**  
U.S. Edition • April 20, 2019 | Print Edition | Video

8

Can dead  
brains come  
**back to life?**

**TORONTO STAR**

9

Pig brains partially revived hours **after death**—what it means for people



10

A dead pig's brain was brought **back to life**



11

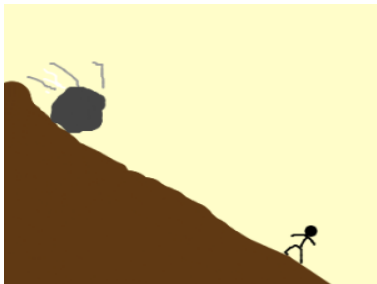
**Frankenswine:** Scientists bring brains of dead pigs 'back to life'



12

Brain death  
=  
death ?

13



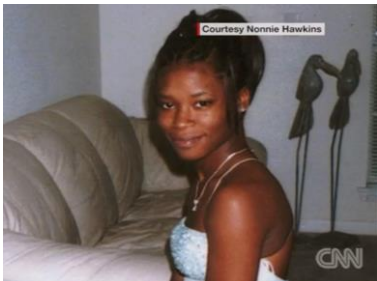
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Case

15



16



17

November  
2003

18



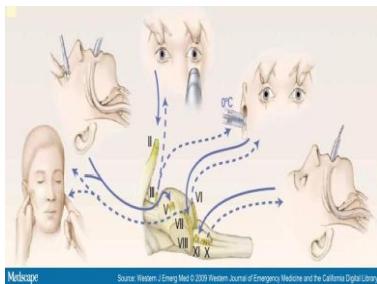
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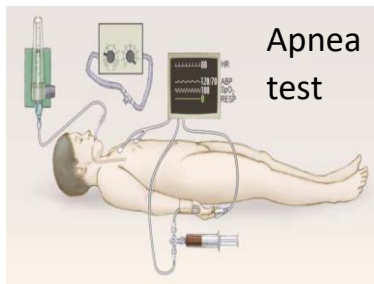
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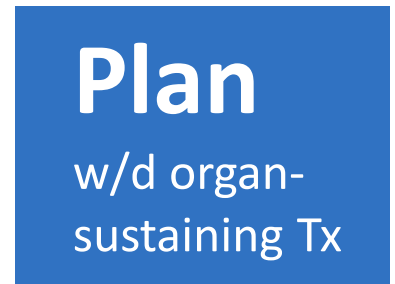
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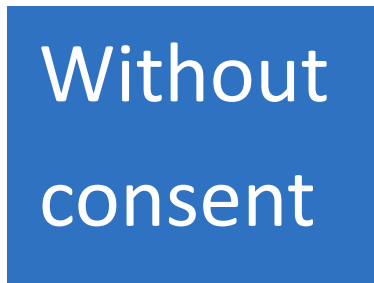
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26



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“tortuous  
termination  
of life support”

28



29

Alive | Dead

30

Alive  
Medical futility conflict  
Family decision

31

Dead  
Straightforward  
Clinician control

32

MERITER HOSPITAL  
Madison, WI  
  
GUIDELINES REGARDING DECISIONS  
TO WITHHOLD, USE OR WITHDRAW  
LIFE-SUSTAINING TREATMENT

33

SECTION	4 THE DECISION-MAKING PROCESS	PAGE
4.1	Diagnosis, Prognosis and Uncertainties	7
4.2	Patient Surrogate Makes the Decision in Dialogue with the Physician	7
4.3	Discussion of Benefits and Burdens	8
4.4	When Patient Capacity is Uncertain or Fluctuates	8
4.5	When the Patient Clearly Lacks Capacity	8
4.6	Deciding Whether to Withhold and Brain Death Definition	9
4.7	Care of Infants and Minors with Life-Threatening Conditions	10
4.8	Documenting the Decision	11

34

“decision-making  
process is unnecessary  
when the patient meets  
... brain death” (4.63)

35



36

Dead  
↓  
w/d okay

37

2006 -  
2011

38

May  
2019

39

What's  
**different**  
today?

40

Roadmap

41

**4** parts

42

Part **1**

43

Intro  
to BD

44

Part **2**

45

Resistance  
to BD is  
**growing**

46

Part **3**

47

**Consequences**  
of resistance

48

Part **4**

49

**5** legal  
attacks  
on BD

50

**1968**

51



52



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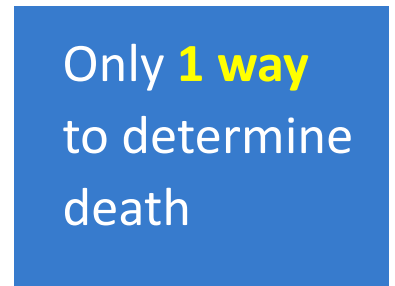
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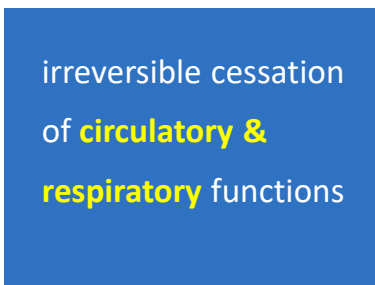
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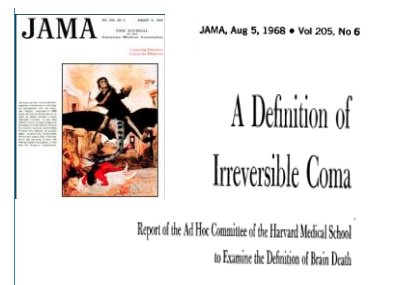
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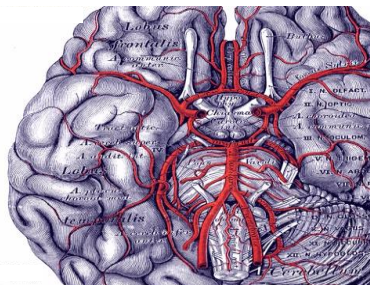


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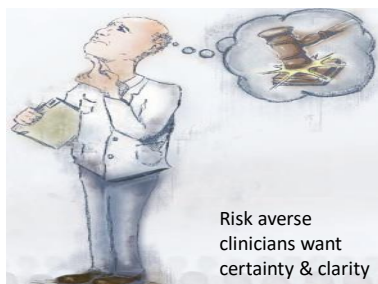
64

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.**

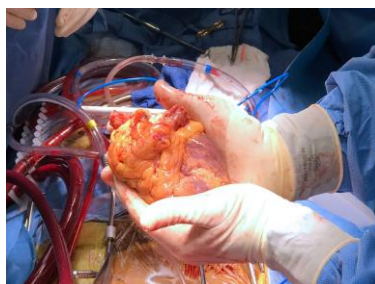
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### Legislation Proposed to Recognize Brain Death

LOS ANGELES (PTS) — Proposed legislation recognizing so-called brain death will be drafted here, according to Dept. Dist. Atty. John W. Miner. He said it will not define brain death.

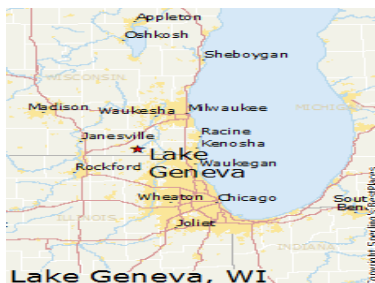
The Los Angeles County district attorney's vital organ transplant committee decided that a clear definition of death is needed now that heart transplants have raised the question as to whether the donor is technically dead or alive at the time his heart is taken.

Such legislation would be the first in the nation recognizing brain death — death when the brain ceases to function, even though the heart and respiration are continued by artificial means.

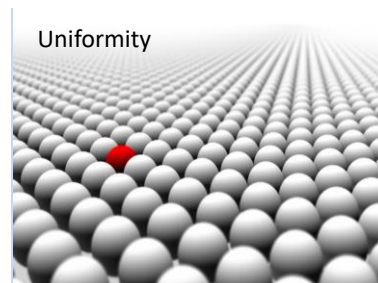
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72



# 1981

73



74

# UDDA

75

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

76

# Brain death = Death

77

# Wis. Stat. 146.71

S.B. 327 (1981), Ch. 134

78

# All 56 US jurisdictions

79

# Legally **settled** since 1980s

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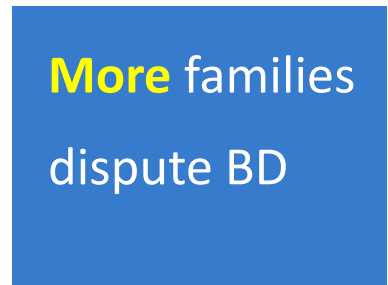
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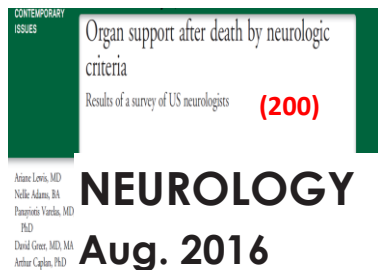
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90



91

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

92



93



94

“**reject** this diagnosis”

“**deviate** from standard procedures”

95

**Not** just USA

96



97

Conflict: **10%**

56 BD cases

2014-2016

98

**More** conflict

99

# Palliative care literature

100

Ethics Roundtable

## Life Support After Brain Death

Steven J. Baumrucker, MD, FAAHPM, FAAFP<sup>1</sup>,  
Laura Hutchinson, ANP<sup>2</sup>, Matt Stolick, PhD<sup>1</sup>,  
Gregory T. Carter, MD, MS<sup>1</sup>, Rev. Karrie Oertli, DMin<sup>2</sup>,  
Leslie Sillim Schmidt, MSSW, MA<sup>1</sup>, and Russell W. Adkins, JD<sup>1</sup>

101

American Journal of Hospice & Palliative Medicine®  
1-7  
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sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1049909114263863  
ajph.sagepub.com  
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## Addressing Religious or Cultural Opposition to Brain Death Diagnosis

Donald O. Johnson, MS, RN ◊ Christine G. Westphal, MSH, NP, ACNS, ACHPN, FPCN

102

Vol. 49 No. 2 August 2010

Journal of Pain and Symptom Management 309

### Ethical Issues in Palliative Care

Series Editors: Muriel Gillick, MD, and Gregg K. VandeKieft, MD, MA

## Brain Death: Ethical Challenges to Palliative Care Concepts of Family Care

Solomon Liao, MD and Shihō Ito, MD

103

Commentary

## The Death Debate: Penumbra Conundrum

Robert F. Johnson, MD, MEd ◊

104

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2016, Vol. 31(12) 1413-1416  
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DOI: 10.1177/1049909116270288  
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# Many cases to court

105

# 2016 - 2018

106



107

# Why?

108

1

109

Diagnostic  
confusion

110



111

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

112

“He’s in a **coma**.”  
“With rehab/time  
he’ll get better.”

113



114

2

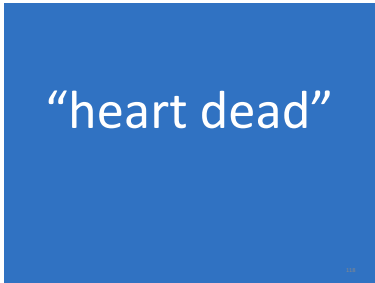
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Linguistic  
Confusion

116

“Brain dead”  
implies not  
**really** dead

117



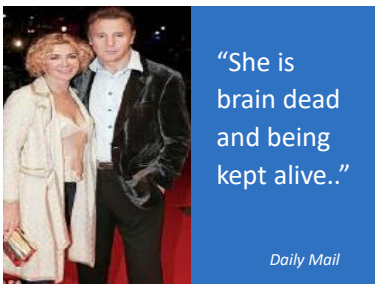
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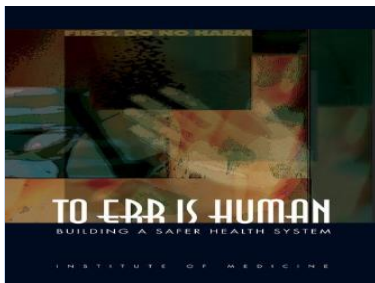
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125



126



Heart disease	600,000
Cancer	600,000
<b>Medical error</b>	<b>400,000</b>
COPD	140,000
Stroke	130,000
Accidents	120,000

127

Brain death  
medical  
error

128

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

By SIBAN DONALDSON JAMES on GOOD MORNING AMERICA  
May 11, 2014



129

Los Angeles Times

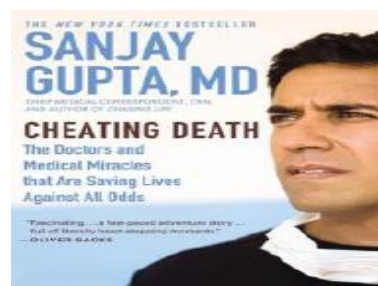
**Close call** in death ruling of potential organ donor

John Foster at Fresno Community  
(April 12, 2007)

130



131



132

“They were declared brain dead. It was written in their charts . . . here they are sitting up talking to me”

133

Negligent  
errors

134

More  
culpable  
errors

135



Hootan  
Roozrok

136



post-gazette.com  
Pittsburgh Post-Gazette  
\$1.2 million settlement in 'organ  
harvest' case  
November 19, 2012 12:00 AM

137



Randall Bianchi  
Chicago

138

Mistrust  
Confusion  
Diagnostic  
Linguistic

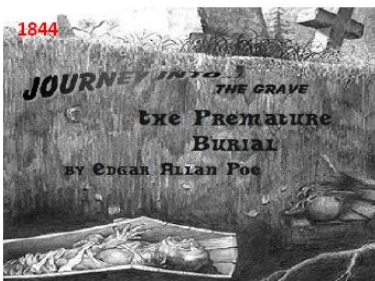
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Taphophobia

141



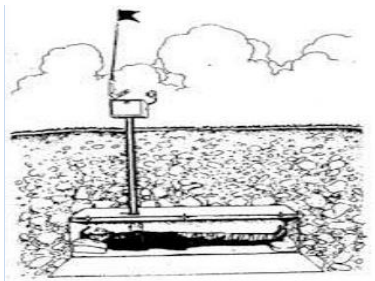
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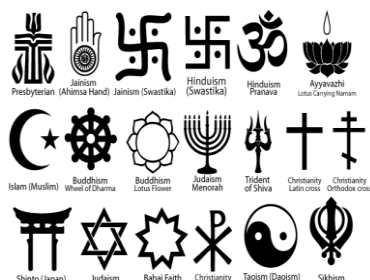
146

Taphophobia  
people want  
to be **sure**

147

5

148



149

6

150

Miracles

151



152

57%

Trauma Death  
Views of the Public and Trauma Professionals on Death and Dying From Injuries  
Lemworth M. Jacobs, MD, MPPE; Karyl Burns, RN, PhD; Barbara Bennett Jacobs, RN, MPPE, PhD, CHPN  
*Arch Surg.* 2008;143(8):730-735

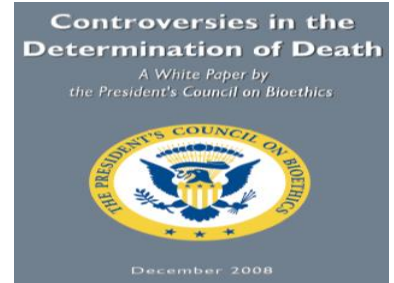
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159



Request Legal Help

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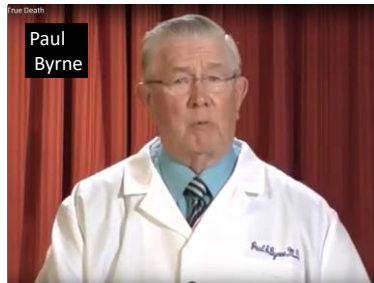
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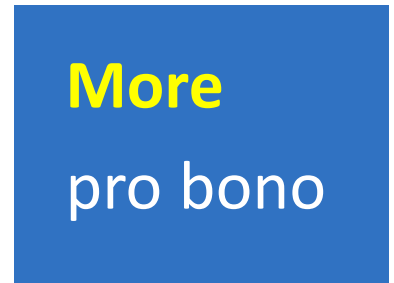
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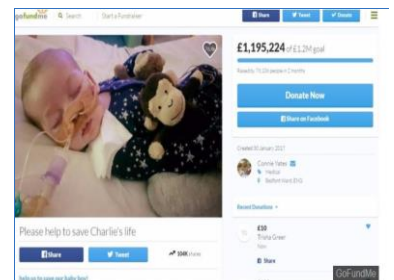
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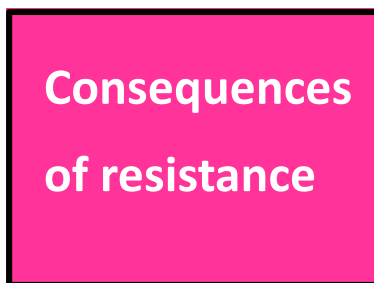
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167



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171

Harm  
innocent  
3<sup>rd</sup> parties

172

1

173



174

2

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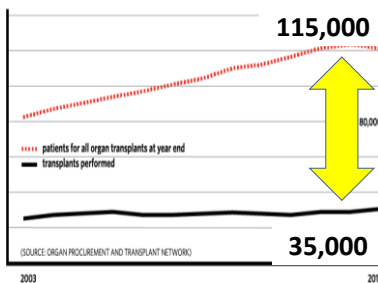
176

2018: More transplants than ever



There were more than **10,700** deceased donors in 2018.  
8th consecutive record breaking year.

177



178

5 Types of dispute

179

Least  
↓  
Most serious

180

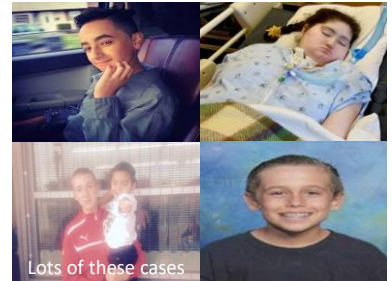


Attack  
1 of 5

181

Confusion  
Mistrust

182



183

Just 1  
example

184



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186



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189

Wrong before  
Wrong now

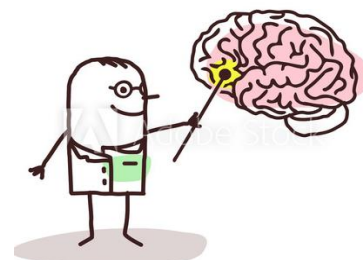
190



SUPERIOR COURT  
OF CALIFORNIA  
COUNTY OF ORANGE

Injunction against  
removing ventilator

191



192



193



194

Other  
tools

195

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

196

JAMA PARENT PAGE

The Journal of the American Medical Association

**Brain Death**

**A** patient dies when brain function ceases, the heart stops beating, and breathing and blood circulation stops. Because life-support techniques have become so advanced, it is possible that even in the face of total injury or irreversible illness, the heart can be kept beating with machines, and respiration (breathing) can be artificially performed with a ventilator. The concept of brain death developed as an answer to these advanced medical techniques that can maintain some body functions. Brain death, as understood in 150-year medical practice, occurs when there is no function in the entire brain. The brainstem is the part of the brain that controls breathing and circulation and controls conscious and all 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 true death. The March 18, 2008, issue of JAMA includes an article about brain death. This Patient Page is based on our publication in the May 14, 2008, issue of JAMA.

**CLINICAL CRITERIA FOR BRAIN DEATH**

- No response to any stimulus (no movement, withdrawal of grip, or blinking)
- No breathing efforts when taken off the ventilator (the apnea test)
- Pupils dilated and not responsive to light
- No gag reflex, or 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 show abnormalities such as bleeding, displacement, massive stroke, brain injury, or swollen brain (edema)
- Electroencephalography (EEG) records electrical brain activity. If brain death is present, the EEG will show no activity.

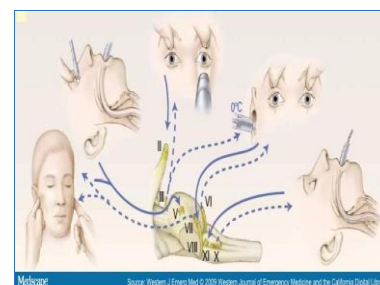
**RESEARCH INFORMATION**

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

**HOW TO LOCATE IT**

• To find this and countless JAMA

197



198



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

199

That's  
**1<sup>st</sup>** attack  
 on BD

200

**Attack**  
**2 of 5**

201

Want  
 religious  
 exemption

202



203

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

204

Religious objection → No death by BD

205

Pt may  
**satisfy**  
 BD criteria

206

**BUT**

207

May **not**  
declare  
death

208

**Until**  
death by  
CP criteria

209

Rejected  
**everywhere**  
outside NJ

210

Still  
asked for

211



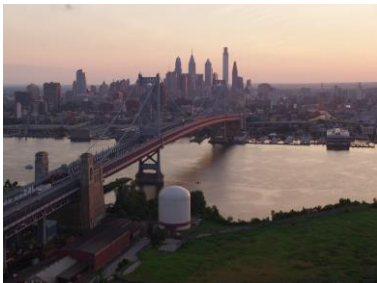
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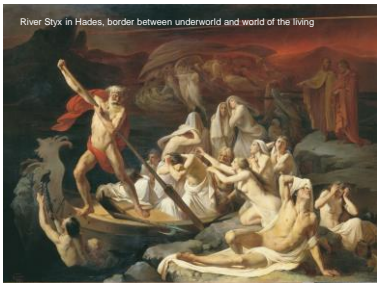
213



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

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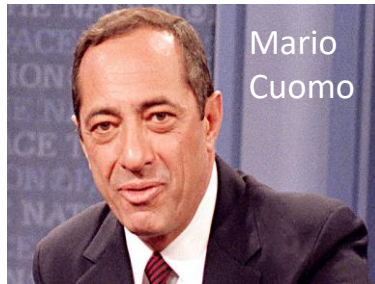
Introduced by Assembly Member Katz

March 4, 1987

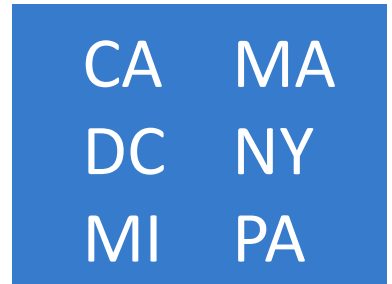
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**California**  
 rejected legislation

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221



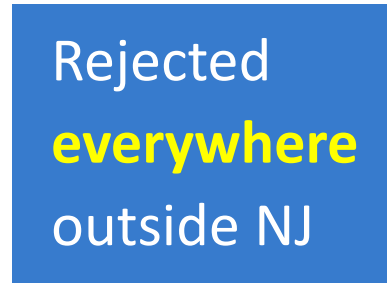
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223



224



225



BUT

226

New cases

227

1

228



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BD guidelines “failed to . . . accommodate . . . religious beliefs, . . . violate . . . constitutional and human rights”

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2

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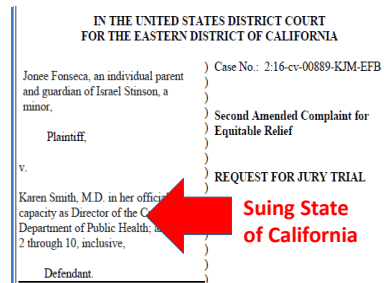




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236



237

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

238

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

239



240



241



242

**NEW YORK STATE DEPARTMENT OF HEALTH**  
**GUIDELINES FOR DETERMINING BRAIN DEATH**  
**DECEMBER 2005**

243

“Hospitals must establish **written procedures** for reasonable accommodation”

244

Free choice  
24 hours

245

**BUT**

246



247

May see **more** of these cases

248



249

That's **2<sup>nd</sup>** attack on BD

250

**Attack  
3 of 5**

251

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

252

Some try to  
**prevent**  
BD diagnosis

253

**Why?**  
this strategy

254

Clinician  
duties  
**after** BD

255

**Limited**

256

*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.**”

257

*Views & Reviews*  
**CMAA**  
California Medical Association  
**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, RN; R.B. Miller, MD; and M. Siegel, MD  
“once death . . . diagnosed . .  
. **discontinue** support . . .”

258

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

259

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

Consent  
**not**  
required

260

Dead → Not a  
patient

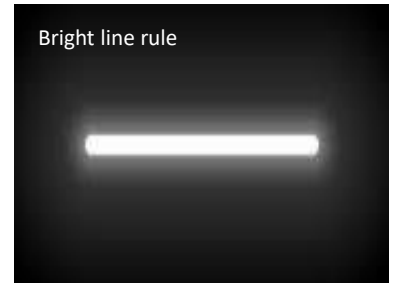
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Not a patient → No Tx duty

262



263



264

No post-BD treatment rights

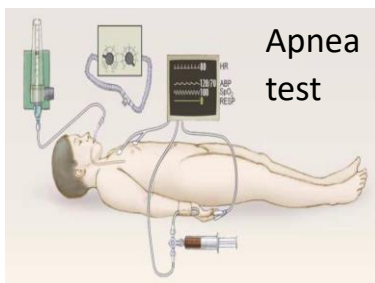
265

So,

266

Focus on pre-BD rights

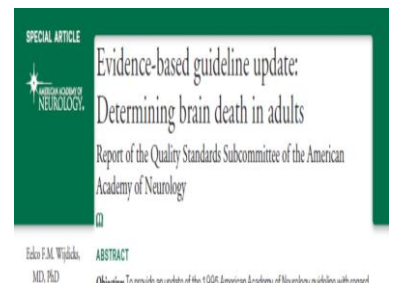
267



268

Final confirmatory test

269



270



Clinical Report—Guidelines for the Determination of Brain Death in Infants and Children: An Update of the 1987 Task Force Recommendations

Thomas A. Nakagawa, MD, Stephen Ashwal, MD, Mott

271

BUT

272

More family refusals

273



274

Parental refusals

275



276

No apnea test  
↓  
No BD

277

No BD  
↓  
Treatment duties continue until CP

278

Practically, same as NJ religious exemption

279

**Opt out**  
BD

280

No apnea test →  
**ancillary** tests

281

But **same**  
consent  
question

282

Must clinicians  
**honor** the  
refusal?

283

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

284



285

**Yes**

286

**Allen  
Callaway**

287



288

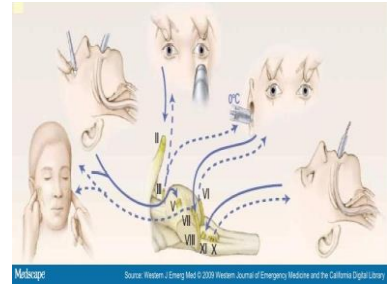




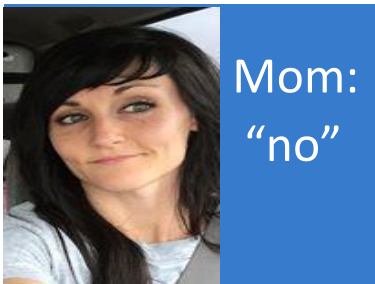
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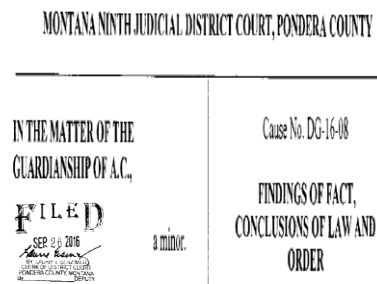
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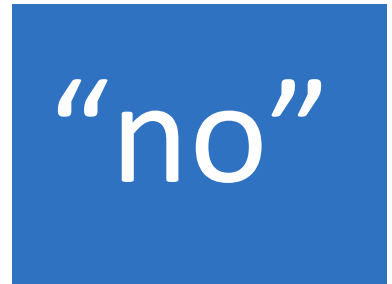
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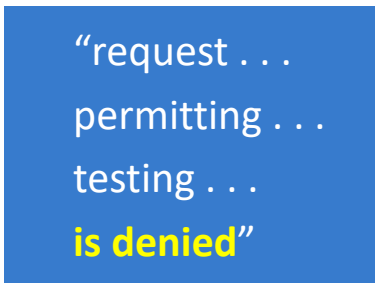
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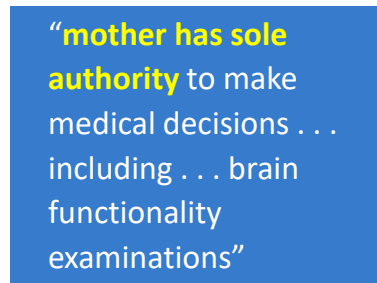
293



294



295



296



297



298



299

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

300

MT said **“yes”**

301

KS also said **“yes”**

302



303



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

304

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

305

CA also said **“yes”**

306



Alex Pierce - drowned

307

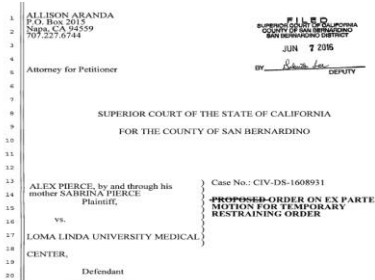


308



Refuse apnea test

309



310



Israel Stinson

311



312

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

313

MT, KS, CA said **“yes”**

314

Plausible

315

Normally, may not do things to patient without **consent**

316



317



Med Mal

318

**No**

319



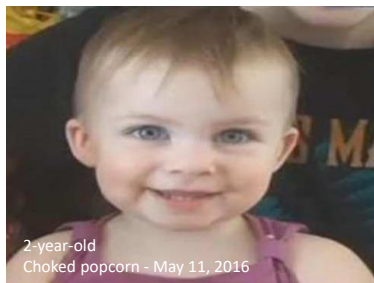
320

**Miranda Lawson**

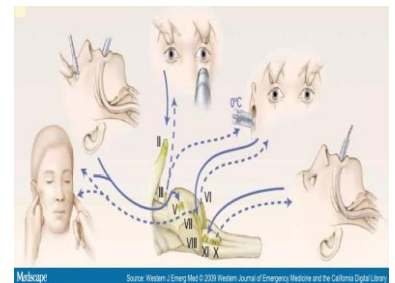
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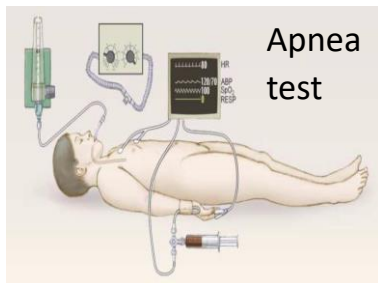
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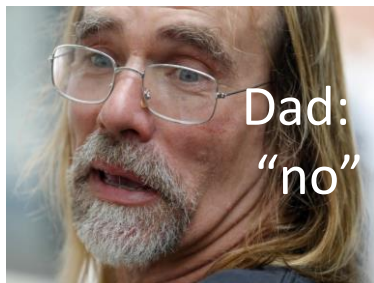
323



324



325



326

I Alison Lawson and Patrick Lawson refuse any sort of "Brain Dead" testing including the "Apnea" test on our daughter Miranda 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 5/20/16  
Patrick Lawson 5/20/16  
Witnessed Kathy Ray 5/20/16  
Witnessed Lynn Rusk 5/20/16

327



328

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

329

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

330

VA said  
"no"

331

NV also  
said "no"

332



333





334

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

335

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

336



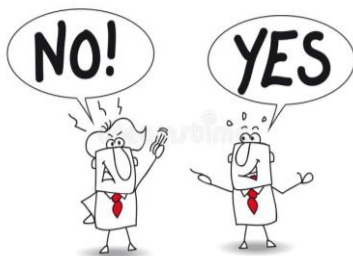
337

“. . . process for determining brain death is underway. **Consent need not be obtained . . .**”

338



339



340

YES	NO
California	Nevada
Kansas	Virginia
Montana	Georgia
	New York

341

Conflict continues

342

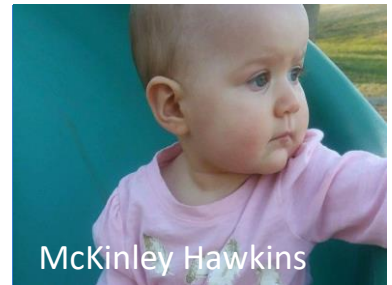




343



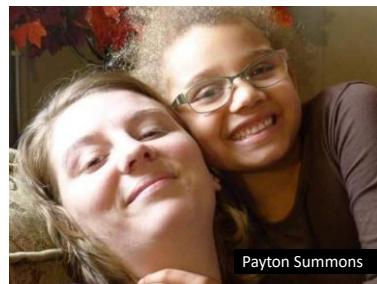
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345



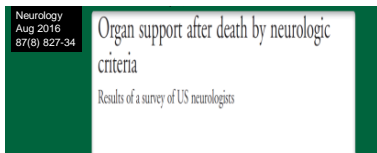
346



347



348



**1/4 neurologists say need consent**

349



350



351

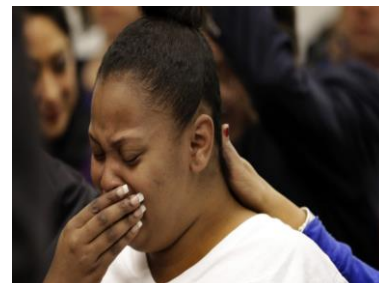


Jahi McMath

352

Dec. 12, 2013  
Declared dead

353



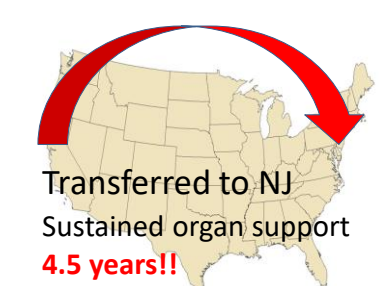
354

Lost lawsuits  
against  
hospital

355



356



Transferred to NJ  
Sustained organ support  
**4.5 years!!**

357

Mar. 2015  
Med Mal lawsuit

358

future  
medical  
expenses

359

Dead people  
do not have  
medical expenses

360

Re-litigate  
status  
as alive

361

Dec. 2013 +	Feb. 2019 -
----------------	----------------

362

Argument  
over **facts**,  
not law

363

Does not attack  
medical criteria  
**themselves**

364



365

Dead at T1  
↓  
Not dead at T2

366

**Problem**

367

**stay** dead

368

Death  
should be  
**irreversible**

369



Collateral estoppel

370

Chance  
to prove

371



“Triable issue . . .  
whether changed  
circumstances”

372

BUT

373



374



375

ATTORNEY OR PARTY WITHOUT ATTORNEY (Name, State Bar number, and address) <b>93578</b> <b>Bruce M. Brunsch</b> Agnew/Brunsch, 26355 Hawthorne Boulevard, 2nd Fl., Torrance, CA 90503 TELEPHONE: (310) 785-1400 FAX: (310) 785-1459 E-MAIL ADDRESS: <b>cbm@brunsch.com</b>		FOR COURT USE ONLY FILED <b>ALAMEDA COUNTY</b> <b>SEP 07 2018</b> CLERK OF THE SUPERIOR COURT <i>[Signature]</i>
ATORNEY FOR PARTY <b>Plaintiff: LATASHA NALAH SPEARS, et al.</b> SUPERIOR COURT OF CALIFORNIA, COUNTY OF ALAMEDA STREET ADDRESS: 24405 Amador Street MAILING ADDRESS: 24405 Amador Street CITY AND ZIP CODE: Hayward, CA 94544 BRANCH NAME: Hayward Hill of Justice		
PLAINTIFF/PETITIONER: <b>LATASHA NALAH SPEARS WINFIELD, et al.</b> DEFENDANT/RESPONDENT: <b>FREDERICK S. ROSEN, M.D., et al.</b>		
REQUEST FOR DISMISSAL		CASE NUMBER: <b>RG 15760730</b>
A confirmed copy will not be returned by the clerk unless a method of return is provided with the document. This form may not be used for dismissal of a derivative action or a class action or of any party or cause of action in a class action. (Cal. Rules of Court, rules 3.760 and 3.776)		
1. TO THE CLERK: Please dismiss this action as follows:		

376

That's 4<sup>th</sup>  
challenge

377

Attack  
5 of 5

378

**Most**  
serious  
attack

379

Are medical  
criteria for BD  
**legally**  
sufficient?

380



381



382

**April 1, 2015**  
Catastrophic anoxic  
brain injury during  
exploratory  
laparotomy

383

**May 28, 2015**  
**Met** AAN criteria  
for brain death

384



385



386

**Dad**  
**loses**

387

**Trial court**  
AAN criteria met  
Aden **is** dead

388



389

**Dad**  
**wins**

390



391

**Irrelevant** if Aden  
meets AAN criteria  
**NOT** the  
“right” criteria

392

**2** reasons

393

**1**

394

**UDDA**

395

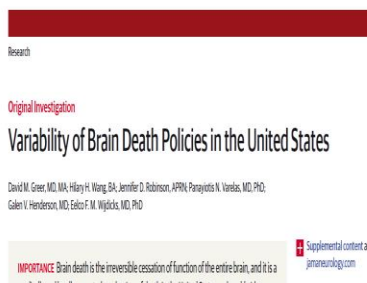
“must be made in  
accordance with  
**accepted medical  
standards**”

396

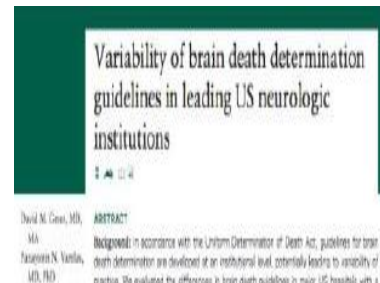




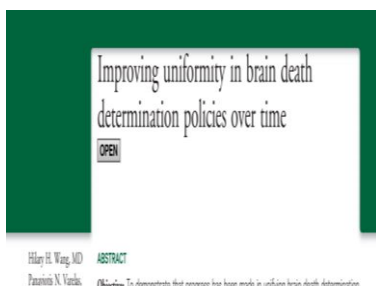
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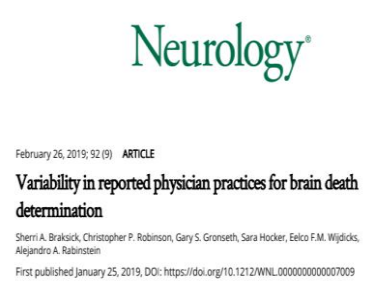
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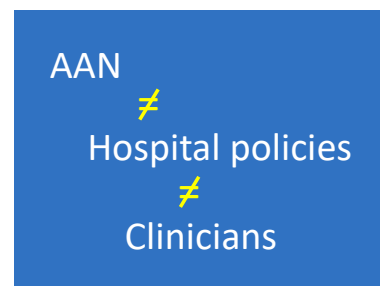
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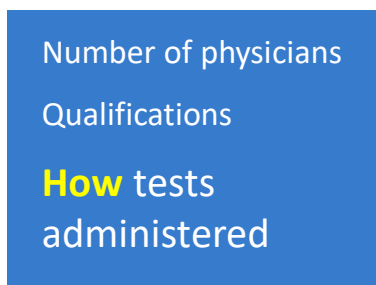
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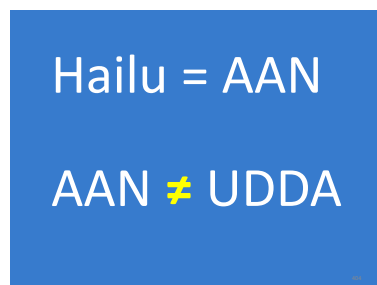
401



402



403



404



405

uncertainty



406

Nevada  
legislature  
steps in

407



408

“accepted  
medical  
standards”

409

AAN / AAP  
authoritative  
criteria

410



411

AAN does not  
measure what  
the UDDA  
requires

412

UDDA

413

Wis. Stat.  
146.71

S.B. 327 (1981), Ch. 134

414

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

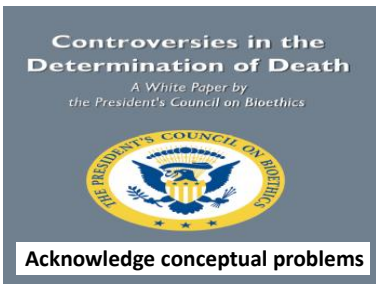
415

**BUT**

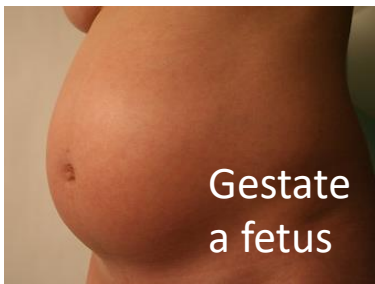
416

Brain dead  
people  
**do** stuff

417



418



419



420



421

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

422

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

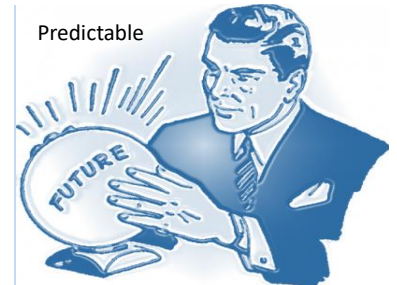
423



424



425



426

UDDA

427

“**silent** on . . .  
diagnostic tests  
. . . procedures”

428

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

429

**Defers** to  
medical  
profession

430

BUT

431



432

Medical criteria  
must measure  
legal standards

433

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

434



435



436



437

Legal standard  
may demand  
more than  
medical criteria

438



439

January  
2019

440

**SPECIAL ARTICLE**

Brain death, the determination of brain death,  
and member guidance for brain death  
accommodation requests

AAN position statement

James A. Russell, DO, MS, Leon G. Epstein, MD, David M. Greer, MD, MA, Matthew Vintchen, MD, PhD,  
Michael A. Rubin, MD, MA, and Aimee Lewis, MD, on behalf of the Brain Death Working Group

Correspondence  
JA Russell  
james.a.russell@ahj.org

Stroke® 2019;49:1-5. doi:10.1212/STROKE.0000000000000750

441

“neuroendocrine function **may be present**”

442

“**not inconsistent** with the whole brain standard of death.”

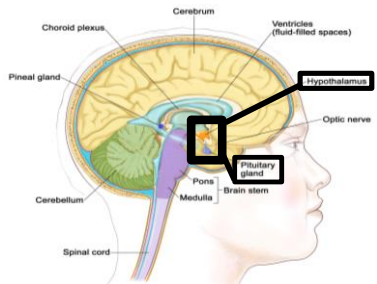
443

UDDA


444

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

445



446

Medically dead  
  
 Legally dead

447

Conclusion

448

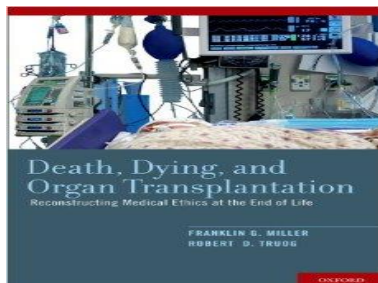
Debate has been **academic**

449

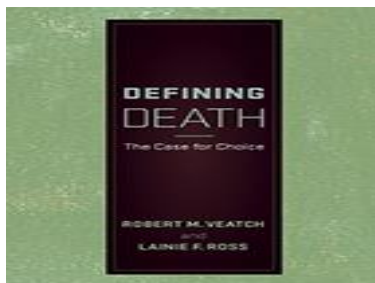


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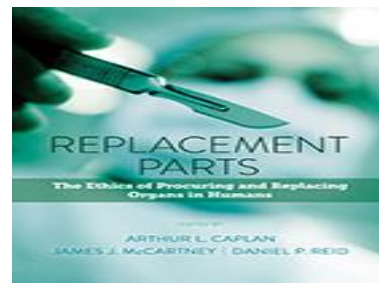




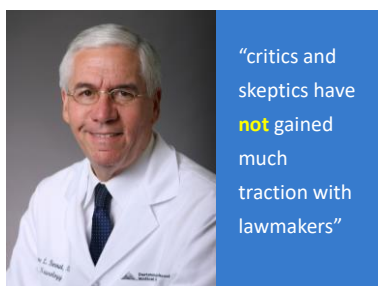
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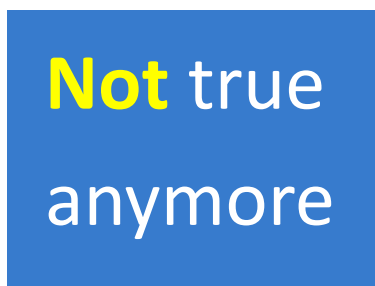
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453



454



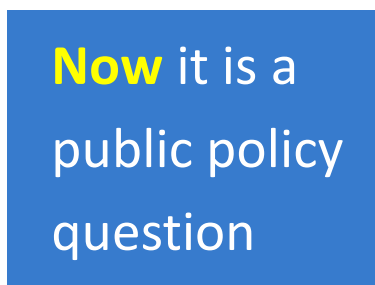
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456



457



458



459



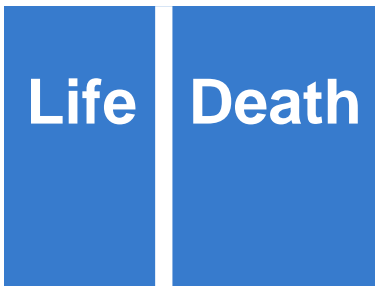
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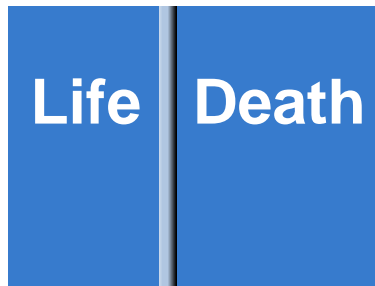
461

“Determining whether a patient is alive or dead is the **most fundamental aspect** of providing medical care.”

462



463



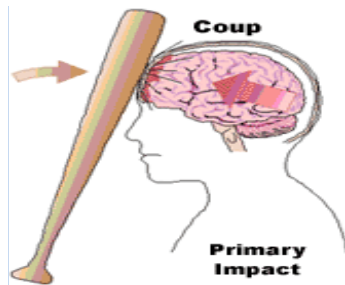
464



465



466



467



468



469



470

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

471



472

She's not only  
**merely** dead,  
  
She's really most  
**sincerely** dead.

473

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B [medicalfutility.blogspot.com](http://medicalfutility.blogspot.com)

474

## References

475

Materials from the  
cases discussed in  
this presentation  
are available at

<http://thaddeuspope.com/braindeath>

476

## Medical Futility Blog

Since July 2007, I have been blogging, almost daily, to [medicalfutility.blogspot.com](http://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 nearly **4 million** direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like WestlawNext and Bioethics.net.

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483

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484