

17th Annual Pediatric Bioethics Conference
Friday, November 1, 2024



1

Brain Death

Strategies for Avoiding,
Managing & Resolving
Conflict between
Families & Clinicians

2

Thaddeus Mason Pope

JD, PhD, HEC-C

3

nothing
to disclose

4



5

Eighth Annual Pediatric Bioethics Conference
Friday, November 6, 2015

Herbert University Center, University of North Florida, 12000 Alumni Dr., Jacksonville, FL 32224



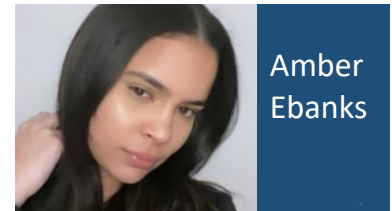
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7



8



9

July 30, 2024

Montefiore Hospital
scheduled surgery

10

but

11



12

August 9, 2024

brain death

13

w/d MV
d/c ICU

14

but

15



16



17

September 6, 2024



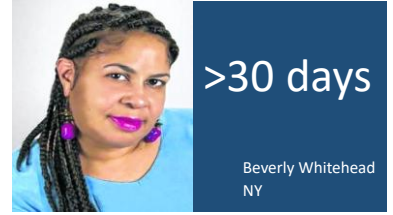
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22



23



24

Pediatr Crit Care Med. 2018 March ; 19(3): 196-203. doi:10.1097/PCC.0000000000001425.

Pediatric Intensive Care Unit (PICU) Length of Stay: Factors Associated with Bed Utilization and Development of a Benchmarking Model

Murray M. Pollack, MD.

**average
PICU stay**

25



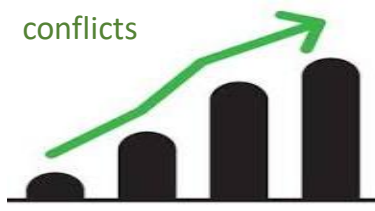
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27



28



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30

more BD conflicts recently escalated to U.S. courts

31



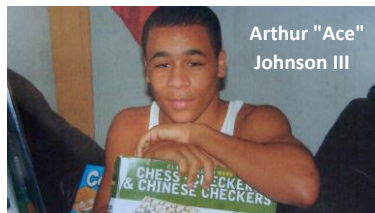
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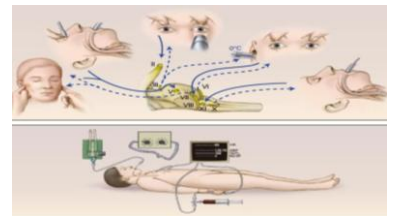
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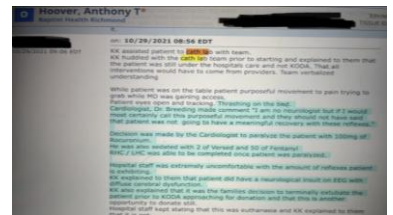
42

Pre-Procedure Checklist	
ASA Scale Assessment	6-A declared brain-dead patient being maintained for harvesting of organ -NS at 10/29/21 0839
T Charges	
Row Name	11/08/21 1628

43



44



45

purposeful movement
thrashing around
crying

46

TJ today

47



48



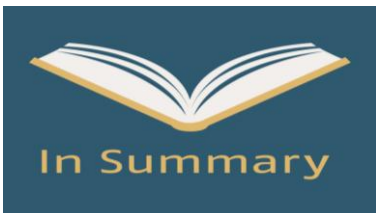
49



50



51



52

more
conflict

53

more
uncertainty

54

more
variability

55

SO ...

56

resolving
conflicts
between clinicians & families

57

roadmap

58

7 parts

59

UDDA

60

6 types BD
conflicts

61



62

UDDA

63

1968

64



65



66



67



68



69



70



71

1968

72

only **1 way** to determine death

73

irreversible cessation of **circulatory & respiratory** functions

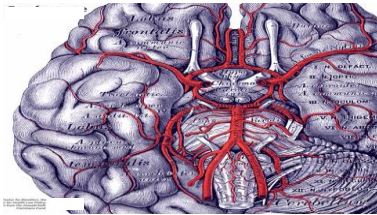
74

but

75



76



77

“no statutory change in law ... necessary”

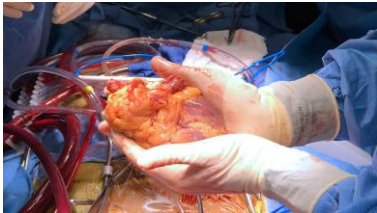
78

wrong

79



80



81

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

82

but

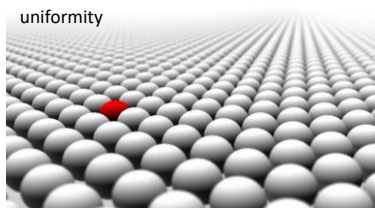
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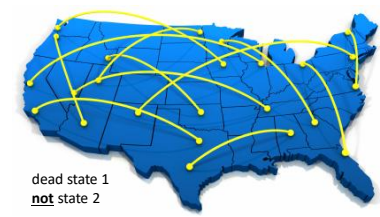
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85



86



87

“status as alive or dead should not depend on the **capricious** question of immediate **locale**”

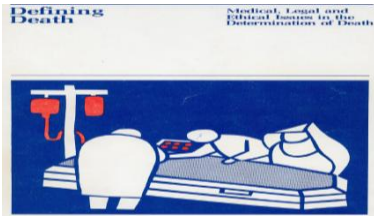
88

1980

89



90



91

UDDA

92

44 words

93

law on death in all U.S. jurisdictions

94



95

Fla. Stat. Ann. § 382.009

96

2 ways to determine death

97

"irreversible cessation of circulatory & respiratory functions"

98

or

99

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

100

circulatory criteria
or
neurologic criteria

101

UDDA

102

eliminate
1970s variability

103

1980

104

44 years

105



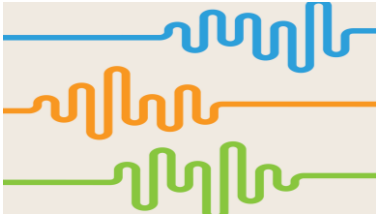
106



107



108



109

state 1
≠
state 2

110

hospital 1
≠
hospital 2

111

MD 1
≠
MD 2

112

law
≠
practice

113

evidence

114

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

115

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

116



117



118

“**reject** this diagnosis”
“**deviate** from standard procedures”

119

no surprise

120



121

“raises the question of whether **brain death** ... is **truly irreversible**”

122

more conflict

123



124

SO...

125



126

2020 2022
2021 2023

127

UDDA →
RUDDA

128

certainty
clarity

129

but

130



131



132



133



134



135

old case

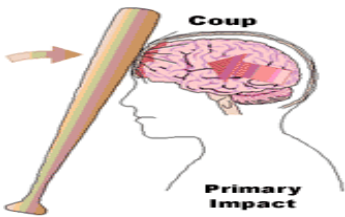
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137



138



139



140



141

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

142



143

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

144



145



146



147



148



149



150



151



152



153

variability
uncertainty

154

enough on
UDDA

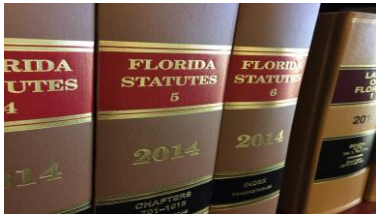
155

6 types BD
disputes

156

how to
respond

157



158



159

BD dispute **1**

160

family
rejects
BD

161

not concept
not criteria

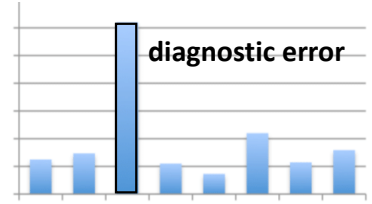
162

as **applied** to
this patient

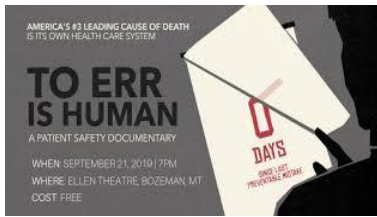
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164



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166



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168



169



170



171

SO ...

172

diagnostic
mistrust

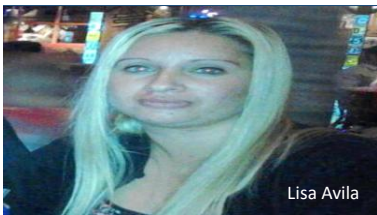
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example of
dispute
resolution

174



175



176



177



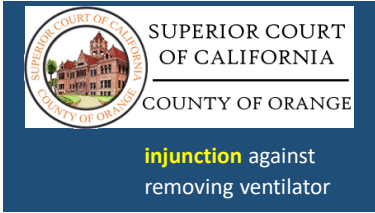
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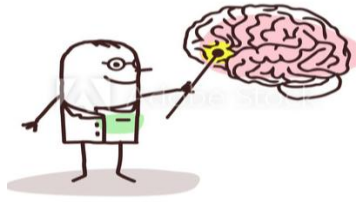
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wrong before
wrong now

180



181



182



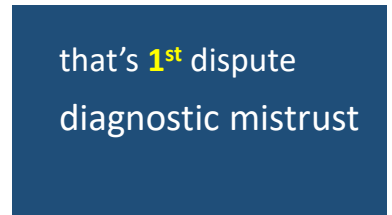
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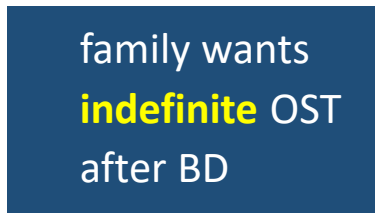
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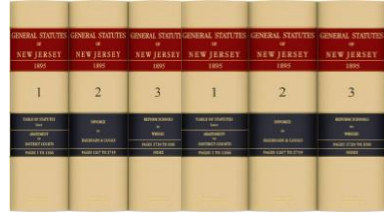
189

“if **heart** beats,
they are alive”

190



191



192

“death ... **shall not**
be declared ... violate
... **religious beliefs** ...”

193

may **not** withdraw
OST because BD

194

religious objection → no death by BD

195

Pt may
satisfy
BD criteria

196

but

197

may not
declare
death

198

until
death by
CP criteria

199



200



201



202



203

Long Survival Following Bacterial Meningitis-Associated Brain Destruction

Susan Reperinger, MD; William P. Fitzgerald, MD; Mathew F. Omogbeh, MB, FRCPC; Roger A. Brumback, MD

ABSTRACT

This report describes the brain autopsy of a boy who at age 11 years experienced an episode of fulminant *Haemophilus influenzae* type b bacterial meningitis, resulting in massive brain destruction and the clinical signs of brain death. However, medical intervention maintained him for an additional two decades. Subsequent autopsy revealed a calcified intracranial spherical structure weighing 750 g and consisting of a calcified shell containing granular material and cystic spaces with no recognizable neural elements grossly or microscopically. This case represents an example of long survival of brain death with a living body. (*J Child Neurol* 2006;21:501-505, DOI 10.1177/0885066605281375)

204

chronic
brain death

205



206

for some patients

BD ≠ death

207



208



209



210



211



212



213



214



215



216



217

will see **more**
of these cases

218



219



220



221



222

yes	accommodation
no	exemption

223

New Jersey

224

not dead → indefinite
duty treat

225

RUDDA

226

dead → temporary
duty treat

227

SO ...

228



229



230



231

no duty to continue
OST indefinitely
except in NJ

232

clinician duties
after BD

233

limited

234

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 ... brain dead ...
 medical support should
 be **discontinued**”

235

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”

236

Guidelines for Physicians: Forgoing Life-Sustaining
 Treatment for Adult Patients
 Joint Committee on Bioethical Ethics
 of the
 Los Angeles County Medical Association
 and
 Los Angeles County Bar Association
 Approved by the Los Angeles County Medical Association Executive 11, 2006
 Approved by the Los Angeles County Bar Association March 22, 2006

“all medical
 interventions
 should be
withdrawn”

237

consent
not
required

238

dead → not a
patient

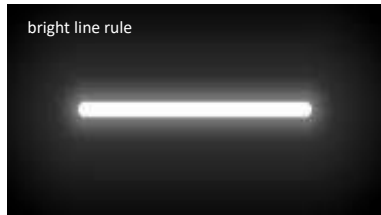
239

not a
patient → **no** Tx
duty

240



241



242

no **post**-BD
treatment rights

243



244

that's 2nd dispute
religious exemption

245

BD dispute 3

246

family wants
limited OST
after BD

247

accommodation

248



249

what

250

“continue **only**
previously ordered
cardiopulmonary
support”

251

“**no** other medical
intervention is
required”

252

how long

253

“reasonably brief period”

254

“amount of time ... to **gather** family ... at the patient's bedside”

255

law **defers** & delegates to hospitals

256

“hospital **shall adopt a policy** for providing ... with a reasonably brief period”

257

<24h

258



259



260

custom & practice **everywhere** else

261

standard
of care

262



263



264



265

“A health-care facility shall adopt a policy for providing the patient’s family with a **reasonably brief period of accommodation**”

266

reasonably brief
period of
accommodation

267

“means an **amount of time** afforded to gather at the patient’s bedside.”

268

“**only required** to continue previously ordered support for circulation and/or respiration. No other medical intervention is required.”

269

IN
OTHER
WORDS

270

default rule

271

dead → no
duty
treat

272

RUDDA

273

dead → **temp**
duty
"treat"

274

SO ...

275

 **TheUpshot**

276

duty to continue
OST reasonably
brief time (~24h)

277

not even

278

bed needed by
a **living** patient

279

law sets only **minimum** duties

280

institutions may offer **more** accommodation than legally required

281

that's **3rd** dispute accommodation

282

BD dispute **4**

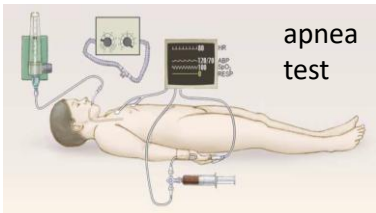
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family objects to BD **testing**

284

must clinicians get **consent** for BD tests?

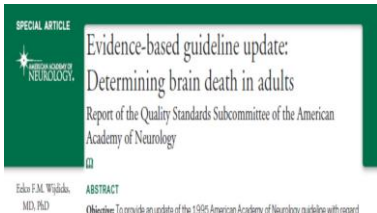
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286

final confirmatory test

287



288

American Academy of Pediatrics
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Guidance for the Clinician in Rendering Pediatric Care

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, Mudd

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Published Ahead of Print on October 11, 2023 as 10.1212/WNL.000000000207740

SPECIAL ARTICLE

Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Guideline

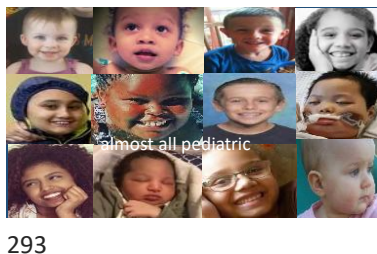
Report of the AAN Guidelines Subcommittee, AAP, CNS, and SCCM

David M. Green, MD, MA,* Matthew P. Kirschner, MD, PhD,* Arina Lewis, MD,* Gary S. Gronseth, MD, Alexander Rae Grant, MD, Stephen Ashwal, MD, Maya A. Balou, MD, MBA, David F. Bauer, MD, MPH, Lori Billingham, MD, MSc, Amanda-Cory, MD, Sonal Parag, MD, MC, Michael A. Rubin, MD, MA, Lori Shuster, MD, Courtney Takahashi, MD, Robert C. Taylor, MEdS, MD, Panayotis Nicolaou Varelis, MD, PhD, Ekow Wigdicks, MD, PhD, Amy Bennett, JD, Scott R. Weisels, MEdS, ELS, and John J. Helberin, MD

Correspondence: American Academy of Neurology guideline@aana.com

Neurology® 2023;88(11-12):doi:10.1212/WNL.000000000207740

290





298

no apnea test
↓
No BD

299

no BD
↓
treatment duties
continue until CP

300

opt out
BD

301

practically, same
as NJ religious
exemption

302

^{NJ} determine **YES**
declare **NO**

303

^{here} determine **NO**
declare **NO**

304

must clinicians
honor the
refusal?

305

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

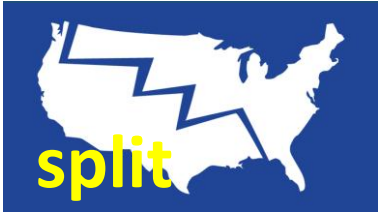
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before
2021

307

variability
uncertainty

308



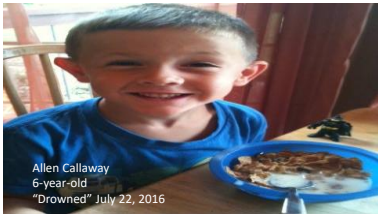
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yes

310



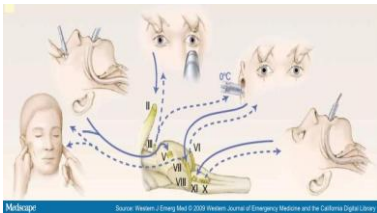
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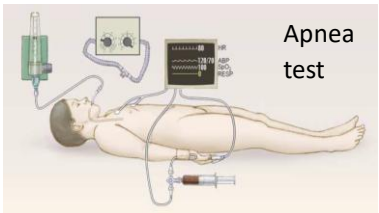
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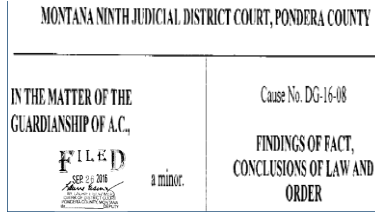
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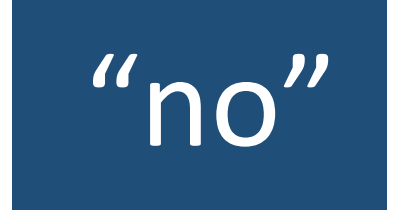
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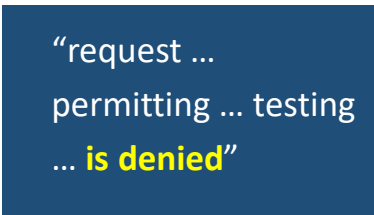
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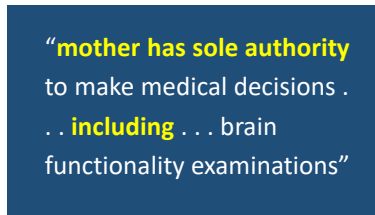
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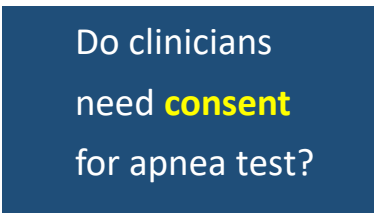
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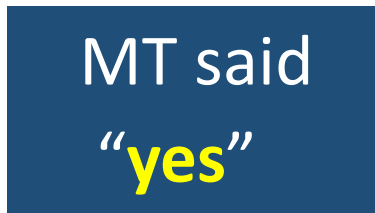
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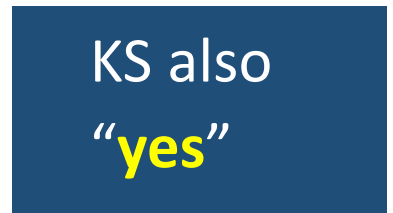
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322



323



324



325

CA also "yes"

326



327



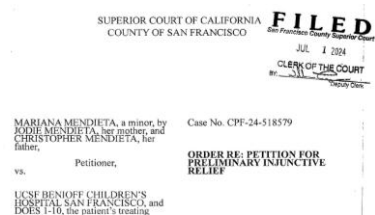
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329



330



331

no more apnea tests

332

plausible

333

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

334



335

no consent = medical battery

no

336



337



338



339



340



341

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POINT AND COUNTERPOINT

1343 **POINT:** Whether Informed Consent Should Be Obtained for Apnea Testing in the Determination of Death by Neurologic Criteria? Yes

1344 **COUNTERPOINT:** Whether Informed Consent Should Be Obtained for Apnea Testing in the Determination of Death by Neurologic Criteria? No

1345 **Related From Dr. Steinhilber**
Dr. Alan Steinhilber

1346 **Related From Dr. Page**
Thudis Dr. Alan Page

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Book | © 2022



Death Determination by Neurologic Criteria

Areas of Consensus and Controversy

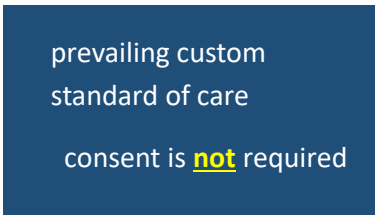
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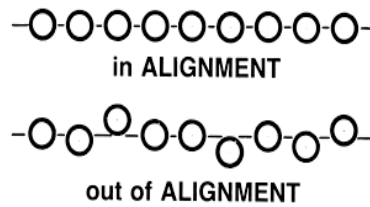
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345



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347

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Correspondence: American Academy of Neurology guidelines@aan.com

*Neurology® 2023;91(10):21. doi:10.1212/WNL.000000000207740

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JAMA | Special Communication

Determination of Brain Death/Death by Neurologic Criteria

The World Brain Death Project

David M. Greer, MD, MA, Sam D. Shemie, MD, Ariane Lewis, MD, Sylvia Torrance, BSc, Paragjits Vardeas, MD, Fernando J. Goldenberg, MD

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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 Kirschner, MD, PhD

Correspondence

350

351

“moral authority ...
to perform ... **without**
obligation to obtain
informed consent.”

352

“professional
responsibility”

353



RUDDA

354

consent
not required

355

but

356

“Before a physician initiates
the determination ...
reasonable efforts ...
notify a patient’s family
that such a determination
will soon begin.”

357



358



359

“next of kin ... shall be
notified as soon as
practicable of the
procedures to
determine death ...”

360

 **TheUpshot**

361



362

generally,
consent **not**
required

363

notify family
of testing

364

but you do **not**
need consent

365

that's **4th** dispute
consent to test

366

BD dispute **5**

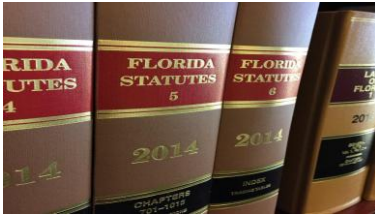
367

family claims BD
does **not follow**
“accepted medical
standards”

368

UDDA

369



370

when making determinations of irreversible cessation

371

“accordance with **accepted medical standards**”

372

but

373

which medical standards are accepted ?

374



375

variability

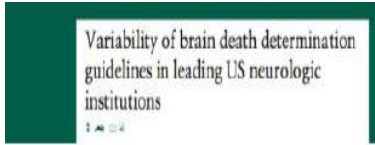
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377



378



David M. Green, MD, MA
Naseema N. Vasthi, 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

379



380



381



382

Neurology®

February 26, 2019; 92 (9) ARTICLE

Variability in reported physician practices for brain death determination

Sherri A. Braksick, Christopher P. Robinson, Gary S. Gronseth, Sara Hocker, Eelco F.M. Wijdicks, Alejandro A. Rabinstein

383

number of physicians
qualifications
how tests administered

384



385

Fla. Stat. Ann.
§ 382.009

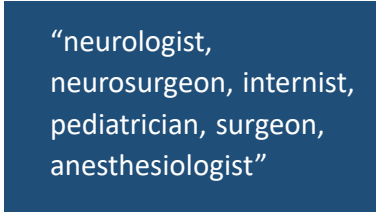
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2 physicians

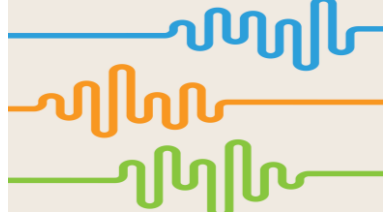
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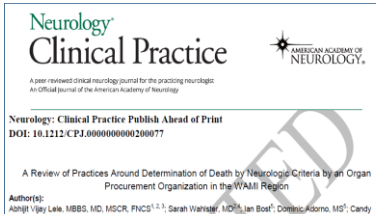
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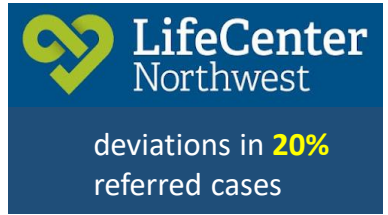
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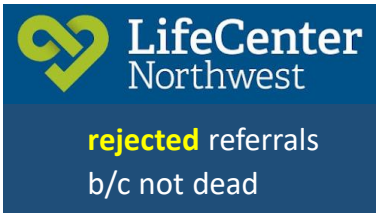
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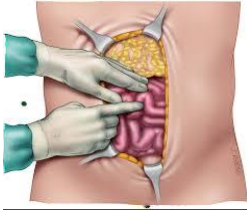
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395



396



brain injury during exploratory laparotomy

397

met AAN criteria for brain death

398



399



400

dad loses

401

trial court AAN criteria met → Aden is dead

402



403

dad wins

404



405

irrelevant if Aden meets AAN criteria
not the "right" criteria

406

AAN guidelines not "accepted medical standards"

407



408



409

amended NUDDA
A.B. 424 (2017)

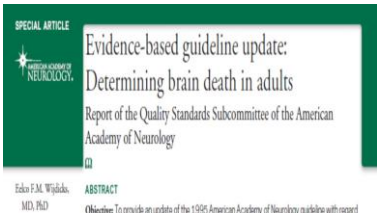
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determination of BD "must be made in accordance with ..."

411

~~accepted medical standards~~

412



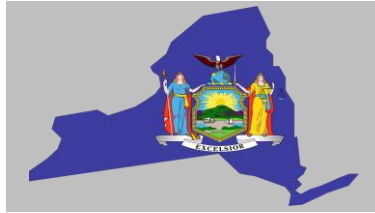
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414



415



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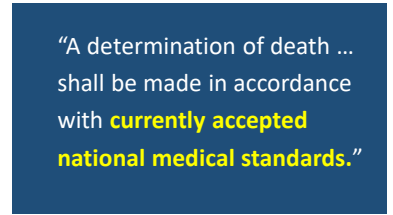
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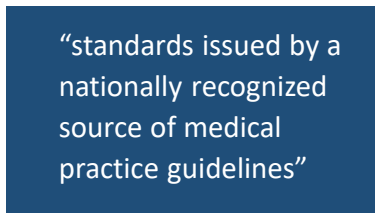
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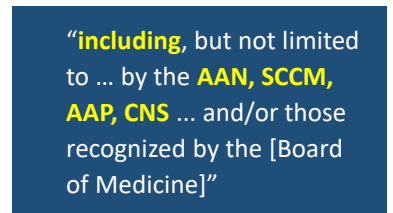
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421



422



423

but

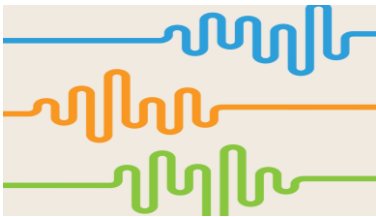
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425



426



427

hospital 1
≠
hospital 2

428

MD 1
≠
MD 2

429

SO ...

430



431

family **may**
have grounds

432

but **no** duty
unless TRO PI

433

that's **5th** dispute
BD fails to
follow AMS

434

BD dispute **6**

435

family contends
BD **violates**
UDDA 2d way

436



437

law | medicine

438

UDDA

439

irreversible cessation
all functions
entire brain

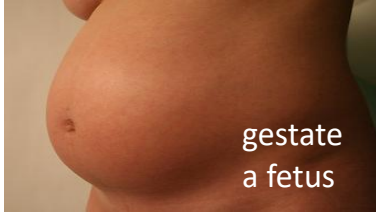
440

but

441

brain dead
people
do stuff

442



443




444

clinicians assess only
some functions
part of brain

445

UDDA requires
all functions
entire brain

446

medically dead

legally dead

447



448



449

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. Green, MD, MA, Matthew Kindler, MD, PhD, Michael A. Rubin, MD, MA, and Allison Lewis, MD, on behalf of the Brain Death Working Group

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Neurology® 2019;92:1-5. doi:10.1212/WNL.0000000000006750

450

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SPECIAL ARTICLE
Pediatric and Adult Brain Death/Death by Neurologic Criteria Consensus Guideline
 Report of the AAN Guidelines Subcommittee, AAP, CNS, and SCCM

David M. Green, MD, MA,* Matthew P. Kirschner, MD, PhD,* Ariana Lewis, MD,* Gary S. Grosseth, MD, Alexander Rae Grant, MD, Stephen Akhond, MD, Maya A. Balala, MD, MBA, Dana F. Bauer, MD, MPH, Lori B. Bingham, MD, MS, Amanda Corey, MD, Sonal Parag, MD, MC, Michael A. Rubin, MD, MA, Lori Shuster, MD, Courtney Takahashi, MD, Robert C. Taylor, MBS, MD, Panayotis Nicolaou Vardoulis, MD, PhD, Esko Wajsbick, MD, PhD, Amy Bennett, JD, Scott R. Weasels, MPA, ELS, and John J. Helberin, MD

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Neurology® 2023;101:1-21. doi:10.1212/WNL.000000000207740

451

patient can
satisfy BD
guidelines

452

dead

453

yet...

454

“neuro-endocrine
function **may be**
present”

455



456

may determine BD
despite function
hypothalamus

457

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

458



459



460



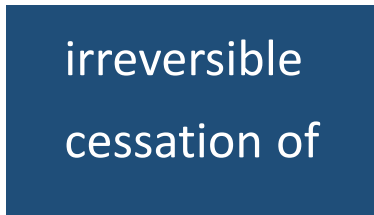
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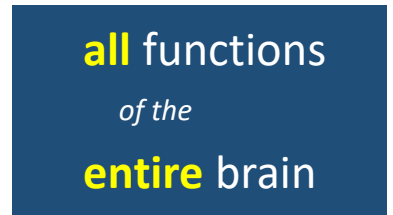
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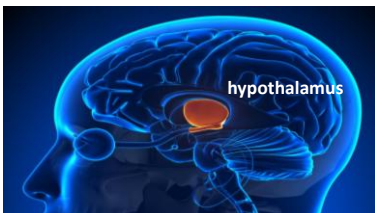
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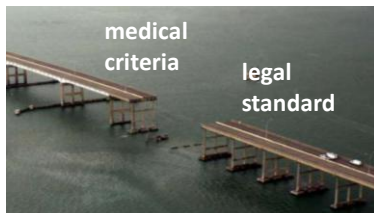
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465



466



467



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A Framework for Revisiting Brain Death: Evaluating Awareness and Attitudes Toward the Neuroscientific and Ethical Debate Around the American Academy of Neurology Brain Death Criteria

Journal of Intensive Care Medicine
1-18
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SAGE

Krishanu Chatterjee, BA¹, Mohamed Y. Rady, BChir, MB (Cantab), MA, MD (Cantab)², Joseph L. Verheijde, PhD, MBA, PT³, and Richard J. Butterfield, MA⁴

469

200 clinicians
Mayo Clinic

470

suppose you
1. use AAN protocol
2. get **positive** result

471

does that show loss of "all functions of the entire brain"?

472



473



474

medical criteria do not require cessation of **all** functions

475

require cessation of **critical** functions

476



477

whole brain death

478

partial
brain death

479



480

but

481

lack authority
to do that

482

analogy

483



484



485



486



487

UDDA gives standards

488

medical profession only **applies** them

489

1. all functions
2. entire brain
3. cessation
4. irreversible

490

legal challenges

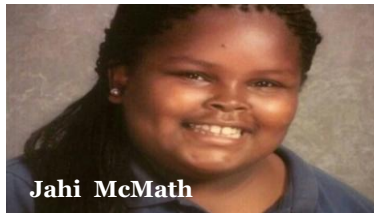
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492

brain death is **also** under attack

493



494

original attack

495

Jahi does not satisfy BD criteria

496

later challenge

497

AAN & AAP Guidelines **themselves**

498

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Attorneys for Plaintiffs

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

CASE NO. RG 15760730

499

Plaintiffs request the opportunity to present evidence and expert testimony that the AAN and AAP Guidelines fail to meet the requirements of California's UDDA that an individual is brain dead only after suffering "an irreversible cessation of all functions of the person's entire brain, including her brain stem".

500

"incalculable disruption
 ... if this court decides the Guidelines do not meet ... UDDA ... criteria"

501

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 By: *[Signature]* Deputy

ATTORNEY FOR PLAINTIFF Defendant James Howard, M.D.
 SUPERIOR COURT OF CALIFORNIA, COUNTY OF ALAMEDA
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 CITY AND ZIP CODE: Hayward, 94544
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PLAINTIFFS/PETITIONER: Latasha Nailah Spears Wakefield, et al.
 DEFENDANT/RESPONDENT: James Howard, M.D., et al.

NOTICE OF ENTRY OF DISMISSAL AND PROOF OF SERVICE
 Personal Injury, Property Damage, or Wrongful Death
 Motor Vehicle Other
 Family Law
 Eminent Domain

CASE NUMBER
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504



Beverly Whitehead

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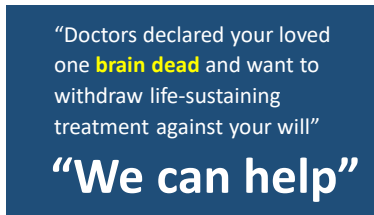
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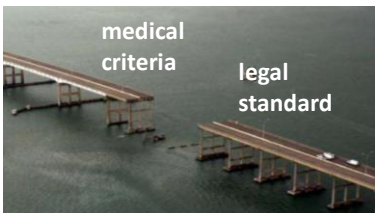
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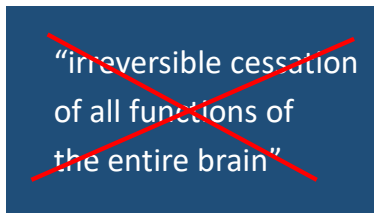
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510



511



512



513

specify
functions

514

no breathing
+
no consciousness

515

“permanent cessation of
spontaneous respiratory
functions **and** permanent
loss of the clinical functions
of the brain necessary for
consciousness”

516

SO ...

517

 **TheUpshot**

518

family **may**
have grounds

519

but **no** duty
unless TRO PI

520

that's **6th** dispute
DBD fails comply
with UDDA

521

conclusion

522

6 types BD conflicts

523

2 groups

524



525

this pt ≠ AAN
AAN ≠ all/entire
AAN ≠ accepted

526



527

omit testing
indefinite accom.
temp. accom.

528



529

you don't need the
patient to be **dead**
to withdraw LST

530

even if BD
contested

531

use your
NBT policy

532

step **1**

533

negotiation
mediation

534

95%

535

step **2**

536

replace
surrogate

537

get consent from
new surrogate

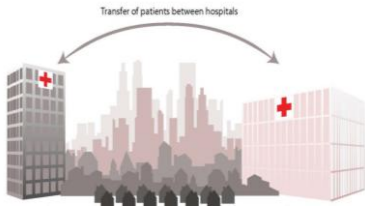
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step **3**

539

transfer

540



541

step 4

542

w/d NBT

543

Thank you!

544

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