

**Simon's Law: Unleashing
Surrogate Authority
to Demand Potentially
Inappropriate Treatment**

University of Kansas Medical Center
April 14, 2017

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Mitchell Hamline School of Law

Nothing
to disclose

Roadmap

4 parts

1

Background
& Context

Simon Crosier

S.B. 85

Kansas is not alone

2

Assessment

Consult mandate

No consent mandate

3

Parents may veto

So what?

No unilateral anyway

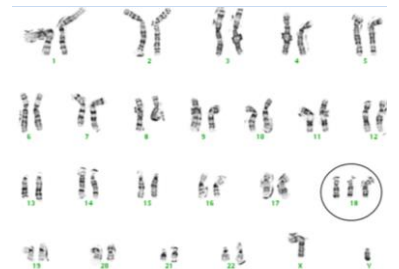
Consensus anyway

Can replace SDM

4

Odd defects

**Simon
Crosier**



DNR

Died 12/03/10
3mo old

Without
parents'
consent

Without
parents'
knowledge

Trisomy 18

“incompatible with life”
“uniformly lethal”



Trisomy 18

13% live 10 years



2015

Mo. H.B. 113

2016

Mo. H.B. 1915

Kan. S.B. 437

2017

Kan. S.B. 85
Kan. H.B. 2307

28

S.B. 85

Senate 3/16



House 3/30



Signed 4/7



Effective

July 1, 2017

29

2 main parts

34

Part 1

35

Share LST policies

“Upon the request . . . **shall disclose** in writing any policies . . . involving resuscitation or life-sustaining measures, including any policies related to treatments deemed non-beneficial, ineffective, futile or inappropriate”

Applies to **all**
patients & LTC
residents

Not a big deal

Already
required by
PSDA

Part 2

**Narrower
Scope**

1

unemancipated
minors

2

“**do-not-resuscitate**
order or similar
physician’s order”

Original bill:

“withhold, withdraw or
... restrictions on **life-
sustaining measures**”

3 Mandates

Re:

DNR

For minor

Mandate 1

Consult

“**shall not** be
instituted . . . unless at
least one parent . . .
has first been
informed”

“reasonable
attempt has been
made to inform the
other parent”

Must **try** both

Must **tell** one

“information must be
provided **both orally
and in writing** unless
... urgency . . .”

No consult



No DNR

Mandate 2

Document

Document **how**
you satisfied the
consult mandate

“[who, when, how
informed parent]
contemporaneously . . .
medical record”

“When only one parent
. . . informed, . . .
reasonable
attempts . . . in . . .
medical record.”

Mandate 3

Accept
veto

“Either parent . . .
may refuse consent
. . . either in writing
or orally.”

“Any such refusal . . .
must be
contemporaneously
recorded . . .
medical record.”



“No [DNR] shall be **instituted** either orally or in writing if there has been such a refusal of consent”

Refuse consent
↓
No DNR

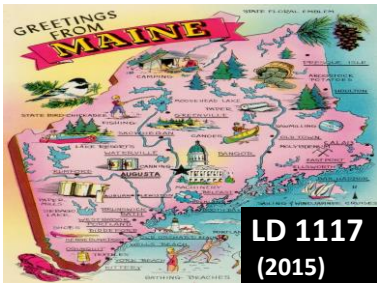
Kansas is **not** alone

**Simon's
Laws**



There is a need for Simon's Law nationwide. In many hospitals across America it is legal for a child to be denied life-sustaining care and for a 'do not resuscitate' order (DNR) to be placed on a child's medical chart without parental knowledge or

[://www.ipetitions.com/petition/simons-law](http://www.ipetitions.com/petition/simons-law)





**More
Red Light
Laws**



Your own
neighbors



Nondiscrimination
in Treatment Act
Nov. 2013

"shall not deny . . .
life-preserving
health care . . .
directed by . . .
[surrogate]"

Medical Treatment
Laws Information Act
Nov. 2014

**Information for Patients and Their Families
Your Medical Treatment Rights Under Oklahoma Law**

No Discrimination Based on Mental Status or Disability:

Medical treatment, care, nutrition or hydration may not be withheld or withdrawn from an incompetent patient because of the mental disability or mental status of the patient.
(Required by Section 3380.9(B) of Title 63 of the Oklahoma Statutes)

What Are Your Rights If A Health Care Provider Denies Life-Preserving Health Care?

* If a patient or person authorized to make health care decisions for the patient directs life-preserving treatment that the health care provider gives to other patients, your health care provider may **not deny** it.

Report suspected violations of any of the laws summarized in this brochure listed above, or attempts to violate any such laws, to the state Licensing Board of the profession(s) of all health care providers involved in the violation.

Oklahoma Board of Medical Licensure and Supervision

www.okmedicalboard.org

405-962-1400

1-800-381-4519 (Toll free outside the 405 area code)

Oklahoma Health Care Providers' Responsibilities and Rights Under Certain Medical Treatment Laws



I hereby certify that I have read this brochure in its entirety and that I understand my legal duties pursuant to the laws described as it

Printed name _____

Licensing entity _____

Employer _____ Date _____

Signature _____

Please complete all information requested above the signature line.

Once complete give to your employer to be placed in your personnel file for a minimum of five (5) calendar years.

**Review & sign
once per year**



“If surrogate directs [LST] . . . provider . . . not wish to provide . . . **shall nonetheless comply . . .**”

47



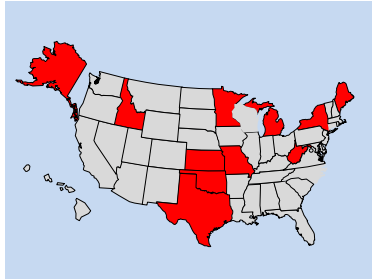
**Discrimination
in Denial of
Life Preserving
Treatment Act**

48

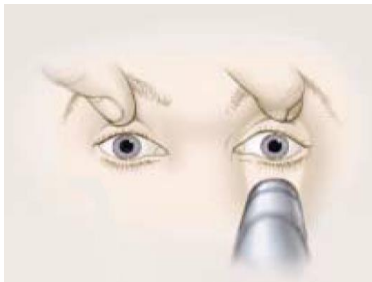
“Health care . . . **may not be . . . denied** if . . . directed by . . . surrogate”

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Those are **legislative** red lights
Also **judicial** red lights



Feb. 1, 2006
TRO **forbid** brain viability exam
Discharged home March 17

Enough background & context

Assessment

Consult mandate

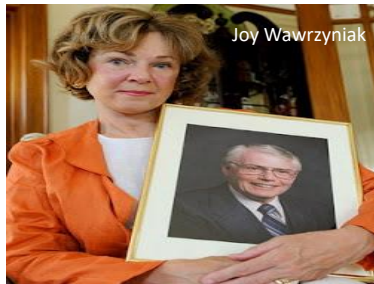
“shall not be instituted . . . unless . . . one parent . . . has first been **informed**”

Be overt
& open

Already
required

101

102



Successful
lawsuits

IIED
NIED

Secretive
Insensitive
Outrageous

103

107

108

Consultation
expected

Distress
foreseeable



Secret DNR
unacceptable

Similarly dishonest
Slow code
Show code

Contrast:
Short code

SB 85 impacts
whether CPR
Not **how** CPR

**There is no
consent
mandate**

Original bill

“No withhold, withdraw .
. . . without the **written
permission”**

Prohibits unilateral DNR

No written permission

 No DNR

As enacted
 “No [DNR] shall be instituted . . . **if** . . . refusal”

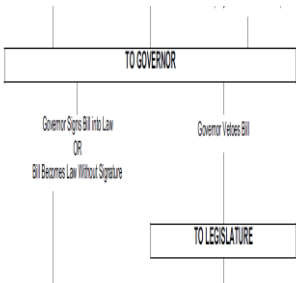
Does **not** prohibit unilateral DNR

No written permission

 DNR okay

No oral permission

 DNR okay



“institute [after] parent **informed**”

Seek assent
Not consent

Open ended question

More directive

Announce plan: "We are going to..."

Silence = assent

Nudge



Behavioral economics increasingly employed

DNR is **default**

Parents must affirmatively object

Parents veto



Honor veto

Parents can veto, so what

No unilateral anyway

Consensus anyway

Can replace SDM

No unilateral anyway

KU MEDICAL CENTER

The University of Kansas

Opponent testimony



Karin Porter-Williamson

“It isn’t a problem in Kansas”



Kathleen Davis

“DNAR would not be implemented without parental consent.”

Cave-in

138

“follow the . . . SDMs **instead** of doing what they feel is appropriate . . .”

CMAJ 2007;177(10):1201-8

BUT

Some unilateral LST limiting in Kansas

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Proponent, SIMON'S LAW SB 437 Kansas Legislature

I am writing in support of Senate Bill No. 437 (Simon's Law). I am a pediatrician from Denver, Colorado, and did my pediatric residency at St. Louis Children's Hospital. I strongly support the 2 sections mentioned in the paragraphs to follow.

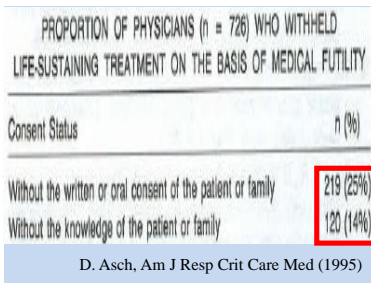


DR. SCOTT SHOWALTER

Related to Section 1. (b) of Bill 437, patients and guardians should have the right to know written policies of a hospital or medical provider concerning life-sustaining or nonbeneficial treatment. Often a patient who is critically sick can be facing life-threatening or disabling events that require complicated medical decisions whether to intervene or withhold treatments. By the same token a parent of a sick child often faces the same situation. Hospitals and medical providers, in such critical situations, should have an obligation, if requested, to inform patients and parents of any written policies that might relate to how they approach life-sustaining treatments and how they determine a treatment might be beneficial or not. If a treatment is considered futile, a patient or parent should have the right to know how this was determined and by what process.

Just as hospitals and medical providers of health care are now required to inform patients of advance directive procedures, I feel being transparent about the information outlined above is just as critical. It would also require very little administrative burden as the policies would only need to be provided if requested.

Section 1. (d) deals with the use resuscitation orders and I fully support the provisions of this section. In my practice and experience, **100% of several instances where parents or guardians were not informed of the such resuscitation orders and only found out after a death that there were never the policy.** This should never happen and Simon's law would prevent this, whether it occurs because of miscommunication or intent. I also feel that in a life-



In what circumstances will a neonatologist decide a patient is not a resuscitation candidate?

Peter Daniel Murray,¹ Denise Esserman,² Mark Randolph Mercurio^{3,4}

Murray PD, et al. J Med Ethics 2016;42:429-434. doi:10.1136/medethics-2015-102941

500 / 3000 members
 American Academy
 of Pediatrics Section
 of Neonatal Perinatal
 Medicine

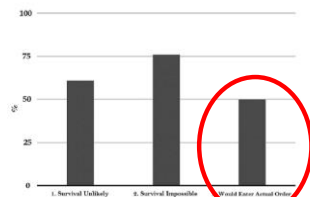


Figure 1 Percentage who answered 'yes' to vignette questions
 1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible when survival is unlikely?
 2. Is a unilateral DNAR permissible when survival is impossible?
 3. Would you actually enter the order in this case?

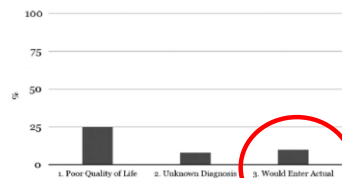


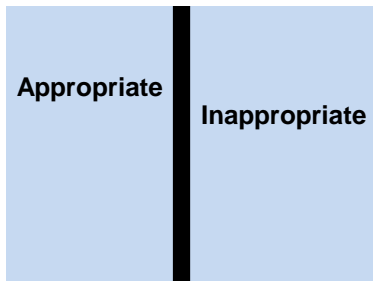
Figure 2 Percentage who answered 'yes' to vignette questions
 1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible in cases associated with a poor quality of life?
 2. Is a unilateral DNAR permissible in cases where the diagnosis is unknown?
 3. Would you enter a unilateral DNAR in this case?

Targeted conduct
 probably **does**
 really happen

**Usually get
 consent
 anyway**

High consensus
 rate in futility
 disputes

Surrogate will
not consent
 when you think
 they should



Advisable	Inadvisable
-----------	-------------

Proportionate	Disproportionate
---------------	------------------

Beneficial	Non-beneficial
------------	----------------

Inside the standard of care	Outside the standard of care
-----------------------------	------------------------------

Therapeutic obstinacy

Surrogate
driven
overtreatment

Clinician	Surrogate
CMO	LSMT

Surrogate will **not** consent to CMO recommendation

95%

PDA



Robust evidence shows PDAs are highly effective

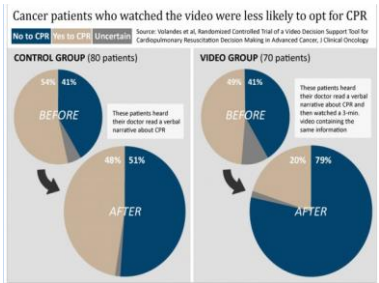
> 130 RCTs



Accurate
Complete
Understandable



Informed surrogates request **less** aggressive treatment



Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement

Alexander A. Kon, MD, FCCM^{1,2}; Judy E. Davidson, DNP, RN, FCCM³;

Wynne Morrison, MD, MBE, FCCM⁴; Marion Davis, MD,

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DOI: 10.1097/CCM.0000000000001386
Critical Care Medicine

PDA → more likely consent

5% → 3%

BUT

“Promise remains elusive”



**Limit on
consensus
rate**

New veto
power relevant
for only 5%
conflicts

BATNA
..... stands for

**Best Alternative To a
Negotiated Agreement**



5% → 8%

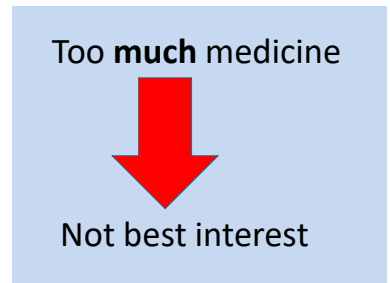
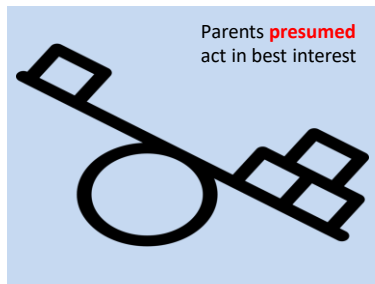
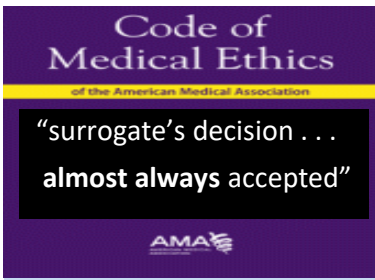
Still no
consent



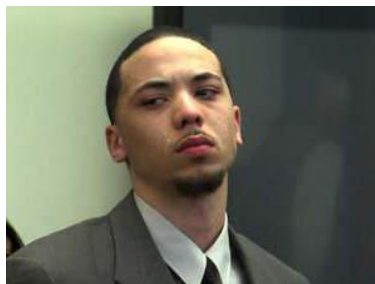
**Replace
Surrogate**

Clinician	Surrogate
CMO	LSMT

Get consent from **new** surrogate



COI



Not
BI

Tuesday
4/11





2 stages

1

Find parents
“unfit”

Too aggressive
↓
Unfit

2

May **new** SDM
authorize DNR



Aiden Stein

Guardian cannot
w/h w/d until
parental rights
terminated

IN THE SUPREME COURT OF THE STATE OF DELAWARE

DAVID HUNT and CAREY LAND, §
§ No. 439/449, 2015
Respondents Below, §
Appellants, § Court Below-Family Court
§ of the State of Delaware,
§ in and for Sussex County
v. §
§
DIVISION OF FAMILY SERVICES § File No.: CS15-01879
and OFFICE OF THE CHILD § Pet. No.: 15-04833
ADVOCATE, §
§
Petitioners Below, §
Appellees. §

Submitted: September 15, 2015
Decided: September 16, 2015

New SDM **may**
authorize DNR

Permanent
custodian


Even without
termination
parental rights

Kan. Stat. 38-2272(d)(6)

“**all** rights”

“court **may**
impose limitation . . .
life-pronging treatment”

Temporary
custodian



PPS Policy and Procedure Manual
Printed Documentation
for April 1, 2017

“When a child in the
custody of the Secretary . . .
requires a Do Not
Resuscitate Order . . . and
parental rights are not
terminated, the **parent(s)
consent shall be sought.**”

“If, after diligent efforts, it is **not possible** to obtain parental permission, **Court consent** shall be sought, unless an emergency exists . . .”

5244(E)

SB 85 overbroad

AMERICAN THORACIC SOCIETY DOCUMENTS

Categories outlined in a new multi-society policy statement

An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement:
Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units

Gabriel T. Bosslet, Theodreas M. Pope, Gordon D. Rubenfield, Bernard Lo, Robert D. Truog, Cynthia H. Rushton,



We help the world breathe
PULMONARY • CRITICAL CARE • SLEEP



The Global Leader in Clinical Chest Medicine



Futile

Legally Proscribed

Legally Discretionary

Potentially inappropriate

Futile

Potentially
inappropriate

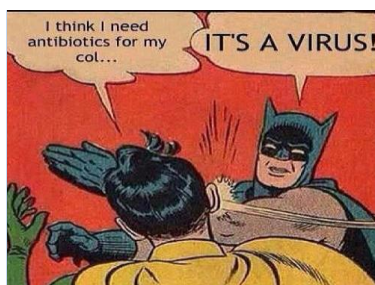
Futile

Interventions
cannot accomplish
physiological goals

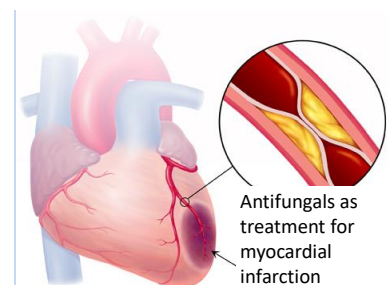
Scientific
impossibility



Example 1



Example 2



Example 3

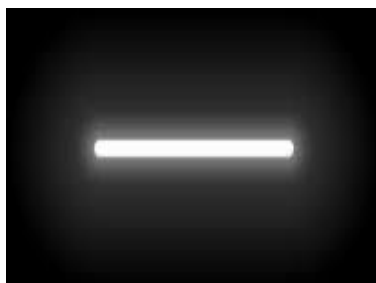


Example 4

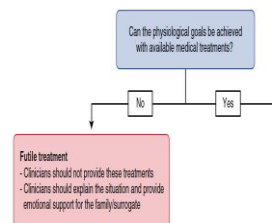


"Futile"

Value free objective



May & should refuse



BUT **not**
 excepted
 by SB 85

**Potentially
 Inappropriate**

Some chance of
 accomplishing the
 effect sought by
 the patient or
 surrogate

Not “futile”
 because
 might “work”

E.g. dialysis for
 permanently
 unconscious
 patient

E.g. vent for
 patient w/ widely
 metastatic cancer

We call them
 “futility disputes”
 . . . BUT . . .

Disputed
 treatment **might**
 keep patient
 alive.

But . . . is that
 chance or
 that outcome
worthwhile

Not a
medical
judgment

Value
judgment

Table 4. Recommended Steps for Resolution of Conflict Regarding Potentially Inappropriate Treatments

1. Before initiation of and throughout the formal conflict-resolution procedure, clinicians should enlist expert consultation to aid in achieving a negotiated agreement.
2. Surrogate(s) should be given clear notification in writing regarding the initiation of the formal conflict-resolution procedure and the steps and timeline to be expected in this process.
3. Clinicians should obtain a second medical opinion to verify the prognosis and the judgment that the requested treatment is inappropriate.
4. There should be case review by an interdisciplinary institutional committee.
5. If the committee agrees with the clinicians, then clinicians should offer the option to seek a willing provider at another institution and should facilitate this process.
6. If the committee agrees with the clinicians and no willing provider can be found, surrogate(s) should be informed of their right to seek case review by an independent appeals body.
- 7a. If the committee or appellate body agrees with the patient or surrogate's request for life-prolonging treatment, clinicians should provide these treatments or transfer the patient to a willing provider.
- 7b. If the committee agrees with the clinicians' judgment, no willing provider can be found, and the surrogate does not seek independent appeal or the appeal affirms the clinicians' position, clinicians may withhold or withdraw the contested treatments and should provide high-quality palliative care.


SB 85 rightly
targets PIT

But wrongly
also targets
“futile”

Original bill

“**shall not apply**”
if “futile because .
. . . withholding not
cause or hasten
death”

No such
exception in
as enacted

Parents veto

CPR even if “futile”

**Thank
you**

References

Medical Futility Blog

Since July 2007, I have been blogging, almost daily, to medicalfutility.blogspot.com.

This blog reports and discusses legislative, judicial, regulatory, medical, and other developments concerning end-of-life medical treatment conflicts. The blog has received **over two million** direct visits. Plus, it is distributed through RSS, email, Twitter, and re-publishers like Westlaw, Bioethics.net, Wellsphere, and Medpedia.

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2015 – 2017

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