Case 2:16-cv-00889-KJM-EFB Document 3 Filed 04/28/16 Page 1 of 3 Kevin T. Snider, State Bar No. 170988 Counsel of record Michael J. Peffer, State Bar. No. 192265 Matthew B. McReynolds, State Bar No. 234797 3 PACIFIC JUSTICE INSTITUTE 4 P.O. Box 276600 Sacramento, CA 95827 5 Tel. (916) 857-6900 6 Fax (916) 857-6902 Email: ksnider@pji.org 7 8 Attorneys for Plaintiffs 9 10 IN THE UNITED STATES DISTRICT COURT FOR THE EASTERN DISTRICT OF CALIFORNIA 11 12) Case No.: Jonee Fonseca, an individual parent 13 and guardian of Israel Stinson, a minor, Plaintiff, 14 **DECLARATION OF ALEXANDER** 15 **SNYDER IN SUPPORT OF** Plaintiffs, PLAINTIFF'S APPLICATION FOR 16 TEMPORARY RESTRAINING 17 ORDER AND REQUEST FOR JUDICIAL NOTICE 18 Kaiser Permanente Medical Center Roseville, Dr. Michael Myette M.D. and 19 Does 1 through 10, inclusive, 20 Defendants. 21 22 23 24 25 26 27 28 DECLARATION OF A. SNYDER

DECLARATION OF ALEXANDER SNIDER

2 3 I, Alexander Snyder, declare as follows:

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- 1. I am an attorney admitted to the State Bar of California, and am not a party to the above-encaptioned case. If called upon as a witness herein, I could and would testify truthfully thereto, of my own personal knowledge, as follows.
- I am the attorney of record in the case Jonee Fonseca, an individual parent and guardian of Israel Stinson, a minor ISRAEL STINSON, by and through JONEE FONSECA, his mother, v. Kaiser Permanente Medical Center Roseville, Dr. Michael Myette M.D. and Does 1 through 10, inclusive, case number S-CV-0037673.
- 3. Said case is filed in the California Superior Court in and for the County of Sacramento.
- 4. I am not admitted to the Federal District Court for the Eastern District of California. As such, last night I contacted another firm, the Pacific Justice Institute, to assist me in filing the case before this Court.
- Attached are true and correct copies of documents that were filed in the 5. Superior Court. These documents are as follows:
 - a. Declaration of Paul A. Byrne, M.D.
 - b. Declaration of Jonee Fonesca
 - c. Declaration of Angela Clemente
- 6. I request that this Court take judicial notice of these State Court filings.
- 7. In that time is of the essence in this emergency motion before the Court to save Israel Stinson's life, I respectfully request that the Court review these declarations in support of the application for a temporary restraining order.

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I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct. Executed this 19th day of January, 2016, County of Solano, City of Fairfield, California. S/ Alexander Snyder Alexander Snyder, Declarant

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Declarant, Paul A. Byrne, M.D., states as follows:

- I have personal knowledge of all the facts contained herein and if called to testify as a witness I
 would and could competently testify thereto.
- 2. I am a physician licensed in Missouri, Nebraska and Ohio. I am Board Certified in Pediatrics and Neonatal-Perinatal Medicine. I have published articles on "brain death" and related topics in the medical literature, law literature and the lay press for more than thirty years. I have been qualified as an expert in matters related to central nervous system dysfunction in Michigan, Ohio, New Jersey, New York, Montana, Nebraska, Missouri, South Carolina, and the United States District Court for the Eastern District of Virginia.
- 3. I have reviewed the medical records of Israel Stinson, a 2-year-old boy, a patient in Kaiser Permanente, Roseville Hospital. I have visited Israel Stinson several times. On April 22 when I visited him, he was in the arms of his mother. A ventilator was in place.
- 4. Israel suffers from the effects of hypoxia and hypothyroidism as well as other conditions that require continuing medical treatment.
- 5. Israel receives treatment for diabetes insipidus by medication administered intravenously. The patient's family and I agree this treatment should continue.
- 6. Israel had asthma attack at home on April 1, 2016. He was taken to Mercy General Hospital ER. He was intubated and then transferred to UC Davis Children's Hospital. ET tube was removed. Shortly thereafter, he had difficulty with breathing and suffered a cardiorespiratory arrest. He was intubated, placed on a ventilator treated with ECMO. After this, a declaration of "brain death" was made.
- 7. Israel has been receiving ventilator support to assist the functioning of his lungs via endotracheal tube since April 1. Tracheostomy has not been done.
- 8. On April 4, Cranial Doppler showed "Near total absence of blood flow into the bilateral cerebral hemispheres."

PATIENT EVALUATION FOR DETERMINATION OF BRAIN DEATH FIRST EXAMINATION AND APNEA TEST

Patient's Name: Israel Stinson

First Exam. Date: 4/4/16 Time: 0932 Temp: 36.4 B/P: 100/65 (78)

A. Preliminary Determination

1. Patient in coma: no

A. Cause of coma: n/a

B. Method by which coma diagnosed: n/a

It is recorded above on April 4 that Israel Stinson is not in coma.

Then, on April 8, the following is recorded, again as "First Examination and Apnea test." So, which is the first?

PATIENT EVALUATION FOR DETERMINATION OF BRAIN DEATH FIRST EXAMINATION AND APNEA TEST

Patient's Name: Israel Stinson

First Exam. Date: 4/8/16 Time: 935 Temp: 36.9 B/P: 106/69 (78)

A. Preliminary Determination

Patient in coma: no

And again, not in coma.

8(a) An apnea test has been done on Israel 3 times. The first test was April 8. He was made acidotic (pH 7.13) and hypercapneic (pCO2 76). It must be noted that the Doppler still recorded blood flow on April 4, which was prior to the first apnea test.

The second apnea test was on April 12. Again he was made severely acidotic (pH 5.15) and severe hypercapneic (p CO2 76).

Apnea test 3 was done April 14. His pCO2 increased to 82 and pH decreased to 7.15. This was not bad enough, so no ventilator life support was continued for another 3 minutes. By then the pH was down to 7.10 and the pCO2 increased to extremely high level of 95.

These tests have caused Israel to have severely elevated levels of carbon dioxide and caused severe acidosis. These tests could not have helped Israel. Further, the third time was after Israel's parents requested that testing not be done.

- 9. Israel's only nutrition since April 1 has been Dextrose, the equivalent of 7-Up. He has been starved of protein, fat and vitamins.
- 9. Israel's parents requested thyroid blood studies April 17. They were done on April 18. Results showed that Israel has hypothyroidism. His parents requested that thyroid be given every 6 hours. Thyroid was started on April 18, but only once a day.
- 10. Prior to April 17/18 Israel was not tested or treated for his hypothyroidism, which has probably been present since his cardiorespiratory arrest. Thyroid hormone is necessary for ordinary normal health and healing of the brain. Lack of thyroid hormone may account for his continued coma. The following information on the importance of hypothyroidism in cases of brain damage is from published studies:
 - A) Shulga A, Blaesse A, Kysenius K, Huttunen HJ, Tanhuanpää K, Saarma M, Rivera C. Thyroxin regulates BDNF expression to promote survival of injured neurons. Mol Cell Neurosci. 2009 Dec;42(4):408-18. doi: 10.1016/j.mcn.2009.09.002. Epub 2009 Sep 16.

Abstract: A growing amount of evidence indicates that neuronal trauma can induce a recapitulation of developmental-like mechanisms for neuronal survival and regeneration. Concurrently, ontogenic dependency of central neurons for brain-derived neurotrophic factor (BDNF) is lost during maturation but is re-acquired after injury. Here we show in organotypic hippocampal slices that thyroxin, the thyroid hormone essential for normal CNS development, induces up-regulation of BDNF upon injury. This change in the effect of thyroxin is crucial to promote survival and regeneration of damaged central neurons. In addition, the effect of thyroxin on the expression of the K-Cl cotransporter (KCC2), a marker of neuronal maturation, is changed from down to up-regulation. Notably, previous results in humans have shown that during the first few days after traumatic brain injury or spinal cord injury, thyroid hormone levels are often diminished. Our data suggest that maintaining normal levels of thyroxin during the early post-traumatic phase of CNS injury could have a therapeutically positive effect.

Available at: http://www.hindawi.com/journals/jtr/2013/312104/

B) Mourouzis I, Politi E, Pantos C. Thyroid hormone and tissue repair: new tricks for an old hormone? J Thyroid Res. 2013;2013:312104. doi: 10.1155/2013/312104. Epub 2013 Feb 25.

Abstract: Although the role of thyroid hormone during embryonic development has long been recognized, its role later in adult life remains largely unknown. However, several lines of evidence show that thyroid hormone is crucial to the response to stress and to poststress recovery and repair. Along this line, TH administration in almost every tissue resulted in tissue repair after various injuries including ischemia, chemical insults, induction of inflammation, or exposure to radiation. This novel action may be of therapeutic relevance, and thyroid hormone may constitute a paradigm for pharmacologic-induced tissue repair/regeneration.

C) Shulga A, Rivera C. Interplay between thyroxin, BDNF and GABA in injured neurons. Neuroscience. 2013 Jun 3;239:241-52. doi: 10.1016/j.neuroscience.2012.12.007. Epub 2012 Dec 13.

Abstract: Accumulating experimental evidence suggests that groups of neurons in the CNS might react to pathological insults by activating developmental-like programs for survival, regeneration and re-establishment of lost connections. For instance, in cell and animal models it was shown that after trauma mature central neurons become dependent on brain-derived neurotrophic factor (BDNF) trophic support for survival. This event is preceded by a shift of postsynaptic GABAA receptor-mediated responses from hyperpolarization to developmentallike depolarization. These profound functional changes in GABAA receptor-mediated transmission and the requirement of injured neurons for BDNF trophic support are interdependent. Thyroid hormones (THs) play a crucial role in the development of the nervous system, having significant effects on dendritic branching, synaptogenesis and axonal growth to name a few. In the adult nervous system TH thyroxin has been shown to have a neuroprotective effect and to promote regeneration in experimental trauma models. Interestingly, after trauma there is a qualitative change in the regulatory effect of thyroxin on BDNF expression as well as on GABAergic transmission. In this review we provide an overview of the post-traumatic changes in these signaling systems and discuss the potential significance of their interactions for the development of novel therapeutic strategies.

The results of test of thyroid function of Israel Stinson are:

4/17/16 TSH: 0.07 (normal 0.7-5)

4/17/16: T4: 0.4 (Normal .8-1.7)

Israel's brain (hypothalamus) is not producing sufficient TSH, thyroid stimulating hormone, which has a half-life of only a few minutes.

If image scans are not sensitive enough to detect circulation in his brain, his brain may be only functionally silent but still functionally recoverable if proper treatment is given.

T4 is low and brain edema has turned into brain myxedema. If T4 is given, brain circulation can increase and resume normal levels, thereby restoring normal neurological and hypothalamic function.

- 11. Israel is dependent upon ventilator to keep him alive. Tracheostomy is indicated to facilitate his treatment and care. A tracheostomy needs to be done. If the endotracheal tube is removed, very likely Israel's airway will not remain open for breathing. If Israel is disconnected from the ventilator, he likely would be unable to breathe on his own because of the duration of time he has been on the ventilator.
- 12. With proper medical treatment as proposed by his parents, Israel is likely to continue to live, and may find limited to full recovery of brain function, and may possibly regain consciousness.
- 13. Israel has a beating heart without support by a pacemaker or medications. Israel has circulation and respiration and many interdependent functioning organs including liver, kidneys and pancreas. In spite of low thyroid Israel's body manifests healing. Israel Stinson is a living person who passes urine and would digest food and have bowel movements if he were fed through a nasogastric or PEG tube. These are functions that do not occur in a cadaver after true death.
- 14. Patients in a condition similar to Israel Stinson's clinical state may indeed achieve total or partial neurological recovery even after having fulfilled criteria of "brain death" legally accepted in the State of California, or established anywhere in the world, provided that they receive treatments based on recent scientific findings (although not yet commonly incorporated into medical practice).
- 15. The criteria for "brain death" are multiple and there is no consensus as to which set of criteria to use (Neurology 2008). The criteria supposedly demonstrate alleged brain damage from which the patient cannot recover. However, there are many patients who have recovered after a declaration of "brain death." (See below.) Israel is not deceased; Israel is not a cadaver. Israel has a beating heart with a strong pulse, blood pressure and circulation. Israel makes urine and would digest food and have bowel movements if he is fed. These are indications that Israel is alive.
- 16. Israel needs a warming device, but he is not a cold corpse. His body temperature has not equilibrated with the environmental temperature as would have occurred if Israel were a corpse.

- 17. The latest scientific reports indicate that patients deemed to be "brain dead" are actually neurologically recoverable. I recognize that such treatments are not commonly done. Further it is recognized that the public and the Court must be wondering why doctors don't all agree that "brain death" is true death. Israel, like many others, continues to live in spite of little or no attention to detail necessary for treating a person on a ventilator. Israel, like all of us needs thyroid hormone. Many persons are on thyroid hormone because they would die without it.
- 18. The diagnosis of "brain death" is currently based on the occurrence of severe brain swelling unresponsive to current therapeutic methods. The brain swelling in Israel Stinson began with the cardiorespiratory arrest that occurred more than 3 weeks ago. Progressive expansion of brain swelling raises the pressure inside the skull thereby compressing the blood vessels that supply nutrients and oxygen to the brain tissue itself. Upon reaching maximum levels, the pressure inside the skull may eventually stop the cerebral blood flow causing brain damage. However, Israel Stinson may achieve even complete or nearly complete neurological recovery if he is given proper treatment soon. Every day that passes, Israel is deprived of adequate nutrition and thyroid hormone required for healing.
- 19. The questions presented here refer to (1) the unreliability of methods that have been used to identify death and (2) the fact that no therapeutic methods that would enable brain recovery have been used so far. In fact, the implementation of nutrition and adequate therapeutic methods are being obstructed in the hope that Israel's heart stops beating, thereby precluding his recovery through the implementation of new therapeutic methodologies.
- 20. Israel Stinson's brain is probably supplied by a partially reduced level of blood flow, insufficient to allow full functioning of his brain, such as control of respiratory muscles and production of a hormone controlled by the brain itself. This is called thyroid stimulating hormone, TSH, which then stimulates the thyroid gland to produce its own hormones. With insufficient amount TSH Israel has hypothyroidism. The consequent deficiency of thyroid hormones sustains cerebral edema and prevents proper functioning of the brain that control respiratory muscles.
- 21. On the other hand, partially reduced blood flow to his brain, despite being sufficient to maintain vitality of the brain, is too low to be detected through imaging tests currently used for that purpose. Employing these methods currently used for the declaration of "brain death" confounds NO EVIDENCE of circulation to his brain with actual ABSENCE of circulation to his brain. Both reduced availability of thyroid hormones and partial reduction of brain blood flow also inhibit brain electrical activity, thereby preventing the detection of brain waves on the EEG. The methods currently used for the declaration of "brain death" confound flat brain waves with the lack of vitality of the cerebral cortex. It is noted that EEG has not been done on Israel Stinson.
- 22. In 1975, Joseph, a patient of mine, was on a ventilator for 6 weeks. He wouldn't move or breathe. An EEG was flat without brainwaves, which was interpreted by neurologists as "consistent with cerebral death." It was suggested to stop treatment. I continued to treat him. Eventually, Joseph was weaned from the ventilator, went to school and is now married and has 3 children.
- 23. In 2013, Jahi McMath was in hospital in Oakland, CA. When I visited her in the hospital in Oakland, Jahi was in a condition similar to Israel. A death certificate was issued on Jahi on December 12, 2013. Jahi was transferred to New Jersey where tracheostomy and gastrostomy were done and thyroid medication was given. Multiple neurologists recently evaluated Jahi and found that she no longer fulfills

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any criteria for "brain death. Since jahi has been in New Jersey, she has had her 14th and 15th birthdays. The doctors in Oakland declared Jahi dead and issued a death certificate. Jahi's mother said no to taking Jahi's organs and no to turning off her ventilator. Israel's parents are saying no to taking Israel's organs and to taking away his life support. Just like Jahi's mother!

- 24. The fact that Israel's brain still controls or at least partially controls his blood pressure and temperature and produces some thyroid stimulating hormone indicates that his brain is functioning and not irreversibly damaged. Rather, Israel is in a condition best described in layman's terms as similar to partial hibernation a status to which an insufficient production of thyroid hormones also contributes.
- The administration of thyroid hormone constitutes a fundamental therapeutic method that can reduce brain edema, relieving the pressure of cerebral edema on blood vessels and restoring normal levels of brain blood flow. By reestablishing the normal range of brain blood flow, recovery of his brain can be expected. In other words, he would regain consciousness and breathe on his own (without the aid of mechanical ventilation). That, however, cannot be accomplished by using only a ventilator and not giving adequate nutrition. Israel indeed requires active treatment capable of inducing neurological recovery. Correction of other metabolic disorders may enhance his chances of recovery.
- 26. Even a person in optimal clinical condition would be at risk of death after weeks of hypothyroidism and only sugar (similar to only 7-up). Israel Stinson needs a Court order requiring Kaiser Permanente to actively promote the implementation of all measures necessary for Israel's survival and neurological recovery, including tracheostomy, gastrostomy, thyroid hormone, and proper nutrition to prevent death.
- 27. Israel Stinson needs the following procedures done:
 - a. Tracheostomy and gastrostomy
 - b. Serum T3, T4, TSH and TRH (thyroid releasing hormone).
 - c. Levothyroxine 25 mcg nasoenterically, nasogastrically or IV every 6 hours the first day; dose needs to be adjusted thereafter in accord with TSH, T3 and T4.
 - d. Samples for lab tests for growth hormone (maybe serum samples can be frozen for future non-STAT tests).
 - e. Serum insulin-like growth factor I (IGF-I) to evaluate growth hormone deficiency.
 - f. Parathormone (PTH) and 25(OH)D3 to evaluate vitamin D deficiency and replacement.
 - g. Continue to follow electrolytes (sodium, chloride, potassium, magnesium, total and ionized calcium), creatinine and BUN.
 - h. Continued monitoring of blood gases.
 - i. Serum albumin and protein levels.
 - CBC including WBC with differential and platelet count.
 - k. Urinalysis (including quantitative urine culture and 24-hour urine protein).

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- I. Continue accurate Intake and Output.
- m. Diet with 40 g of protein per day (nasoenterically or nasogastrically). Fat intravenous until feedings are into stomach.
- n. IV fluids (volume and composition to be changed according to daily serum levels of electrolytes (sodium, chloride, potassium, magnesium, total and ionized calcium) and fluid balance.
- Water, nasoenterically or nasogastrically, if necessary to treat hypernatremia volume and frequency according to serum sodium.
- p. Fludrocortisone Acetate (Florinef®) Tablets USP, 0.1 mg one tablet (nasoenterically or nasogastrically) per day;
- q. Prednisone 10 mg (nasoenterically or nasogastrically) twice per day;
- r. Continue Vasopressin IM, or Desmopressin acetate nasal spray (DDAVP synthetic vasopressin analogue) one or two times per day according to urinary output;
- s. Human growth hormone (somatropin) [0.006 mg/kg/day (12 kg \approx 0.07 mg per day)] subcutaneously;
- t. Arginine Alpha Ketoglutarate (AAKG) powder 10 g diluted in water (nasoenterically or nasogastrically) four times per day;
- u. Pyridoxal-phosphate ("coenzymated B6", PLP) sublingual administration four times per day;
- v. Taurine 2 g diluted in water (nasoenterically or nasogastrically) four times per day;
- w. Cholecalciferol 30.000 IU three times per day (nasoenterically or nasogastrically) for 3 days. Then 7,000 IU three times per day (nasoenterically or nasogastrically) from day 4.
- x. Riboflavin 20 mg four times per day (nasoenterically or nasogastrically)
- Folic acid 5 mg two times per day (nasoenterically or nasogastrically).
- Vitamin B12 1,000 mcg once per day (nasoenterically or nasogastrically).
- aa. Concentrate / mercury-free omega-3 (DHA / EPA) 3 cc four times per day (nasoenterically or nasogastrically).
- bb. Chest physiotherapy
- cc. Blood gases; adjust ventilator accordingly.
- dd. Keep oxygen saturation 92-98%
- ee. Air mattress that cycles and rotates air.
- ff. Pressor agents to keep BP at 70-80/50-60.

27. In a situation such as this where continued provision of life-sustaining measures such as ventilator, medications, water and nutrition are at issue, it is my professional judgment that the decision regarding their appropriateness rests with the family, not the medical profession.

References to some of those who have recovered after a declaration of "brain death":

Hospital staff began discussing the prospect of harvesting her organs for donation when she squeezed her mother's hand. Kopf was mistakenly declared dead in hospital but squeezed her mother's hand in 'breathtaking miracle.'

https://www.dropbox.com/s/dtti4hkkx89ikyg/Uber%20Shooting%20Victim%20Abigail%20Kopf%20Going%20From%20Victim%20to%20Survivor%20 %20NBC%20Nightly%20News.mp4?dl=0

Zack Dunlap from Oklahoma. Doctors said he was dead, and a transplant team was ready to take his organs — until a young man came back to life

http://www.msnbc.msn.com/id/23768436/;http://www.lifesitenews.com/ldn/2008/mar/08032709.htm l, March 2008

Rae Kupferschmidt: http://www.lifesitenews.com/ldn/2008/feb/08021508.html, February 2008.

Frenchman began breathing on own as docs prepared to harvest his organs www.msnbc.msn.com/id/25081786

Australian woman survives "brain death" <a href="http://www.lifesitenews.com/news/brain-dead-woman-recovers-after-husband-refuses-to-withdraw-life-support UTM source=LifeSiteNews.com+Daily+Newsletter&utm_campaign=231fd2c2c9-LifeSiteNews_com_US_Headlines05_12_2011&utm_medium=email

Val Thomas from West Virginia

WOMAN WAKES AFTER HEART STOPPED, RIGOR MORTIS SET IN

http://www.foxnews.com/story/0,2933,357463,00.html

http://www.lifesitenews.com/ldn/2008/may/08052709.html, May 2008.

An unconscious man almost dissected alive: http://www.lifesitenews.com/ldn/2008/jun/08061308.html, June 2008

Gloria Cruz: http://www.lifesitenews.com/news/brain-dead-woman-recovers-after-husband-refuses-to-withdraw-life-support/,May 2011

Madeleine Gauron: http://www.lifesitenews.com/news/brain-dead-quebec-woman-wakes-up-after-family-refuses-organ-donation,July 2011

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References that "brain death" is not true death include:

Joffe, A. Brain Death is Not Death: A Critique of the Concept, Criterion, and Tests of Brain Death. Reviews in the Neurosciences, 20, 187-198 (2009), and Rix, 1990; McCullagh, 1993; Evans, 1994; Jones, 1995; Watanabe, 1997; Cranford, 1998; Potts et al., 2000; Taylor, 1997; Reuter, 2001; Lock, 2002; Byrne and Weaver, 2004; Zamperetti et al., 2004; de Mattei, 2006; Joffe, 2007; Truog, 2007; Karakatsanis, 2008; Verheijde et al., 2009. Even the President's Council on Bioethics (2008), in its white paper, has rejected "brain death" as true death.

VERIFICATION

I declare under penalty of perjury under the law of the State of California that the foregoing is true and correct.

Signature: Paul A. Byrn W

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PAPER

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}

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Correspondence to Dr Peter Daniel Murray, Division of Newborn Medicine, Department of Pediatrics, Tufts University School of Medicine, Boston, MA 02111, USA: PMurray2@tuftsmedicalcenter.

Received 7 July 2015 Revised 9 February 2016 Accepted 22 February 2016 **ABSTRACT**

Objective The purpose of this study was to determine the opinions of practising neonatologists regarding the ethical permissibility of unilateral Do Not Attempt Resuscitation (DNAR) decisions in the neonatal intensive care unit.

Study design An anonymous survey regarding the permissibility of unilateral DNAR orders for three clinical vignettes was sent to members of the American Academy of Pediatrics Section of Perinatal Medicine. Results There were 490 out of a possible 3000 respondents (16%). A majority (76%) responded that a unilateral DNAR decision would be permissible in cases for which survival was felt to be impossible. A minority (25%) responded 'yes' when asked if a unilateral DNAR order would be permissible based solely on neurological

Conclusions A majority of neonatologists believed unilateral DNAR decisions are ethically permissible if survival is felt to be impossible, but not permissible based solely on poor neurological prognosis. This has significant implications for clinical care.

INTRODUCTION

A unilateral Do Not Attempt Resuscitation (DNAR) order refers to a decision by a physician/medical team that is made without permission or assent from the patient or the patient's surrogate decisionmaker. Possible justifications might include the belief that an attempted resuscitation would offer no benefit to the patient, or that any possible benefit would be outweighed by the burdens to the patient. Proponents of unilateral DNAR decisions assert that they avoid unnecessary and painful interventions at the end of life. Various medical associations, including the American Medical Association (AMA), have published codes of ethics that allow physicians not to provide interventions that they do not feel would be beneficial, but determination of which interventions might be beneficial is often nebulous.2 3 Opponents of unilateral DNAR orders argue that they usurp the patients' or surrogate decision-makers' ethical and legal authority to make decisions.4

While there is acknowledgement that the parents' right to make decisions for their child is generally to be respected, the physician's responsibilities sometimes include protecting the patient from treatment considered harmful or inhumane.5 We believe that neonatologists have particular familiarity with the concept of unilateral DNAR decisions, given that they are, at times, consulted regarding care and possible resuscitation for an

infant below the threshold of viability, and might at times decide to forgo attempts at resuscitation without explicitly seeking parental agreement, in cases wherein survival is felt to be impossible.6 We hypothesised that a substantial portion of neonacologists would therefore acknowledge that they find unilateral DNAR decisions ethically acceptable in at least some circumstances.

STUDY DESIGN

An anonymous survey was sent to members of the American Academy of Pediatrics Section of (now the Section on Perinatal Medicine Neonatal-Perinatal Medicine) using surveymonkey. com. The consent was implied by completion of the survey. The survey consisted of three clinical vignettes followed by questions regarding the permissibility of a unilateral DNAR order for the specific case. Demographic information (years in practice; intensive care unit (ICU) level; unit capacity; the presence of trainees and the presence of a nconatal or paediatric palliative care service) was also collected in an attempt to determine the effect of these characteristics on neonatologists' willingness to place a unilateral DNAR order. The survey was sent on 4 September 2014 to the 3000 members of the American Academy of Pediatrics Section of Perinatal Medicine who had an email address listed with the section listscrve and remained open for 2 weeks.

Hypothetical vignettes were designed to determine neonatologists' opinions regarding the ethical permissibility of unilateral DNAR orders in three settings: (1) a patient unlikely to survive a resuscitation, (2) a patient who may survive a resuscitation but would be neurologically devastated and (3) a patient for whom there is no curative treatment available (box 1). The first vignette concerned Frank, a preterm infant born at 22+5 weeks gestation who, despite intensive efforts, is dying. The neonatologist in this vignette believes the patient will not survive a resuscitation attempt. There has not yet been a discussion with the family in this vignette. The respondents are asked whether placing a unilateral DNAR order is acceptable when survival is felt to be unlikely, and when survival is felt to be impossible, and are then asked if they would place such an order. Methods of conflict mediation in the event of disagreement between the family and the physician regarding a DNAR order were also queried in this vignette.

The second vignette concerned Jennifer, a term female with severe lissencephaly who is having respiratory decompensation. The purpose of this

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Murray PD, et al. J Med Ethics 2016;0:1-6. doi:10.1136/medethics-2015-102941

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vignette was to query the opinion of neonatologists regarding cases in which survival might be possible after a resuscitation, but with poor neurological outcome. Three questions followed this vignette and centred around the permissibility of unilateral DNAR orders in cases where there is poor neurological prognosis.

The third vignette described Franne, a term female who had a pulmonary artery shunt placed shortly after birth, which is now failing. Franne also bears a diagnosis that is associated with a poor neurological prognosis. This vignette was designed to query neonatologists' opinions regarding unilateral DNAR orders in cases for which there are no curative treatments available.

The primary outcome measure was whether or not the queried neonatologist felt the unilateral DNAR order was ethically permissible for the given vignette. χ^2 tests of association were used to determine whether responses differed by the demographic characteristics. Analyses were conducted using SAS

Box 1 Hypothetical vignettes

Vignette 1. Frank is a preterm infant born at 22+5 weeks gestation who is currently 6 days old. He suffered a spontaneous bowel perforation today and a Penrose drain is in place. His heart rate is drifting to the low 100 s. He has a mixed respiratory and metabolic acidosis, with a pH of 6.98-7.04 despite high oscillator settings and bicorbonate boluses. The blood pressure is barely acceptable on maximal vesopressor. support. He has had no urine pulput all day. The attending neonatologist believes the infant is dying and attempts at resuscitation Would be unsuccessful Vignette 2: Jannifer is presumably a term female born to a young mother with no antenatel care. The neonatology team is called to evaluate Jennifer given poor tone. The infant is transferred to the neonatal intensive care unit (NICU) where a more thorough exam reveals mild wrist contractures, moderate hypotonia, a prominent forehead and a small jaw. She experiences apnoea which progresses to respiratory failure by the second day of life. An MAL is performed given her neurological findings and it is consistent with severe lissencephaly: The neonatology fellow asks the attending it she should have a unitateral Do Not Attempt Resuscitation (DNAR) order placed, given her poor neurological outcome and decompensation

Vignette 3: France is a 75 day old temale with complex cardiac disease that necessitated a pulmonary artery shunt given profound pulmonary stenosis and a ductus arteriosus that was not large enough to allow adequate pulmonary blood flow with shunting. This procedure was performed on day of life 57 The treatment team is concerned that France is beginning to outgrow her shunt and is requiring more ventilatory support via her tracheostomy; She has a known syndrome that is associated with profound developmental delay, cardiac disease and seizures Franne suffers from all three. An MRI revealed brain atrophy. Her heart disease is amendable to surgical correction. though the cardiothoracic (CT) surgeon at her home institution refuses to operate given the poor neurological prognosis. A second and third opinion yielded similar results. France is showing more signs of shippt failure and is found to have frequent desaturations and episodes of bradycardia. A unilateral DNAR order is placed in the chart by the attending neonatologist

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V9.3 (Cary, North Carolina, USA). Statistical significance was established at 0.05.

RESULTS

There were 490 responses out of a possible 3000 respondents (16%). Selected demographic data concerning the respondents are provided in table 1. For questions such as 'What is the level of the unit in which you currently practise?', some respondents selected more than one response. For the primary outcome, bar graphs are shown regarding the perceived permissibility of a unilateral DNAR decision for each vignette in figures 1–3.

For the first vignette, when asked if a unilateral DNAR order would be appropriate when survival is felt to be unlikely, 61% of respondents answered yes (Question 1.1). An even greater majority answered in the affirmative (77%) when the question is changed to indicate an infant for whom survival was felt to be impossible (Question 2.1). While a clear majority of respondents answered that a unilateral DNAR order would be permissible if survival was felt to be impossible or unlikely, only 51% of respondents answered that they would actually place such an order themselves in this first vignette (Question 3.1). In cases of physician-parent conflict regarding what is perceived as best for the patient, the vast majority of respondents cited ethics committee consultation as a method of conflict resolution. The next most cited resource was consultation with the medical director or section chief, followed by case discussion with a representative of the cisk management department. Very few respondents answered that they would pursue temporary custody from the courts in cases of physician-parent disagreement.

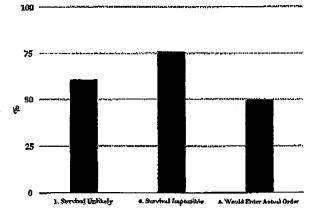


Figure 1 Percentage who answered 'yes' to vignette 1 questions
1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible when survival is unlikely?

- 2. Is a unilateral DNAR permissible when survival is impossible?
- 3. Would you actually enter the order in this case?



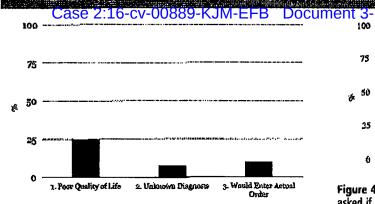


Figure 2 Percentage who answered 'yes' to vignette 2 questions 1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible in cases associated with a poor quality of life?

- 2. Is a unilateral DNAR permissible in cases where the diagnosis is
- 3. Would you enter a unilateral DNAR in this case?

For the second vignette, meant to query opinions regarding a unilateral DNAR order in cases of poor neurological prognosis, 119 (25%) of the neonatologists responded that it was ethically permissible to place a unilateral DNAR order based on a poor neurological prognosis and long-term prospects for poor quality of life (Question 1.2). Forty-nine (10%) answered in the affirmative when asked if they would actually place a unilateral DNAR order themselves based on the information presented in vignette 2 (Question 3.2). Forty-one (8.5%) responded that it was ethically permissible to place a unilateral DNAR order when a diagnosis is unknown (Question 2.2).

Vignette 3 concerned a critically ill infant with a poor neurological prognosis who will succumb to congenital heart disease unless surgically corrected. Neonatologists were asked if a unilateral DNAR order would be appropriate if no curative treatment were available. Two hundred and sixty-six (57%) respondents felt a unilateral DNAR order would be appropriate in such a case (Question 1.3), and 171 (37%) responded that they actually would enact such an order (Question 3.3). Of note, 378 (81%) felt the CT surgery team was justified in not performing a potentially life-saving therapy based on the patient's poor neurological prognosis (Question 2.3).

When analysing the effect of years in practice on opinions regarding permissibility of a unilateral DNAR order, neonatologists with more than 15 years' experience were less likely to

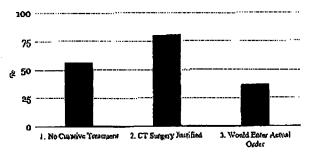


Figure 3 Percentage who answered 'yes' to vignette 3 questions 1. Is a unilateral Do Not Attempt Resuscitation (DNAR) permissible when no other curative therapy exists?

2. Is the cardiothoracic (CT) surgical team justified in not operating based on a poor quality of life?

3. Would you enter a unilateral DNAR in this case?



Figure 4 Percentage who answered 'yes' by years in practice when asked if a unilateral Do Not Attempt Resuscitation (DNAR) was permissible in cases where survival is impossible, p<0.001.

respond 'yes' (p<0.0001) when survival was felt to be impossible, as shown in figure 4, though even in that group a clear majority responded in the affirmative.

Two hundred and eighty-seven (62%) of the respondents answered yes when asked if they had a paediatric or neonatal palliative care service. Approximately 50% (223) of those polled answered that their institution had a written policy requiring parental permission to withhold cardiopulmonary resuscitation (CPR) with 126 (27%) answering that they did not know if such a policy existed in their institution. Seventy-four per cent of polled neonatologists answered that they work with medical trainces in some capacity. There were no statistically significant differences in the opinions regarding the permissibility of a unilateral DNAR order when analysed by the presence of a palliative care service, the presence of a written policy regarding DNAR orders or the presence of medical trainces.

DISCUSSION

In an earlier publication, we explored ethical arguments in favour of, and opposed to, unilateral DNAR orders in paediatrics.1 For this study, we sought to determine the opinions and approaches of a large number of neonatologists with regard to the use of unilateral DNAR orders. It is our understanding and experience that neonatologists commonly invoke what is a de facto unilateral DNAR order in the delivery room setting, in that they commonly do not offer parents the option of attempted resuscitation at less than 22 weeks' gestation, based on the perceived impossibility of success. Such an approach would be consistent with recommendations of the American Academy of Pediatrics,7 the Canadian Pediatric Society8 and the Nuffield Council in the UK.9 Thus, we postulated that a significant percentage of neonatologists would find a unilateral DNAR order to be ethically acceptable for at least some neonatal intensive care unit (NICU) parients, including those for whom survival is felt to be extremely unlikely or impossible. The findings of this survey supported that hypothesis; a majority of the neonatologists surveyed (61%) agreed that a unilateral DNAR order is ethically acceptable when survival is extremely unlikely, and an even greater majority (77%) agreed when survival was felt to be impossible.

While ethical analyses can be found in the literature regarding unilateral DNAR orders, this is, to our knowledge, the first survey to address the opinions of a large number of neonatologists on this question. In 2012, Morparia et al surveyed Paediatric Intensive Care Unit (PICU) physicians and found that the majority of respondents were not in favour of unilateral DNAR decisions in settings with extremely poor prognosis,

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though they did not explicitly stipulate in their vignettes that survival was felt to be impossible. The exception in their study was a case for which the child had been declared brain dead; for that case, a majority of PICU physicians did feel unilateral DNAR was acceptable. Nevertheless, the general disagreement with unilateral DNAR orders noted in the study of PICU physicians stands in contrast to the responses of neonatologists described in this paper.

A potential explanation for this discrepancy may derive from the nconatologists' experiences with extremely preterm newborns delivered below the limit of viability. In our experience, unilateral DNAR decisions are often made in such a setting. While the management of patients in the delivery room (DR) might not be completely analogous to either the PICU or the NICU, that increased familiarity of the neonatologists with unilateral DNAR in the delivery room might nevertheless influence their approach to a patient in the NICU. Put another way, unless a neonatologist routinely offers resuscitation to parents for every extremely preterm newborn, regardless of gestational age or chance of viability, he/she has necessarily had experience with unilateral DNAR decisions. It may then be that extending the same reasoning to the NICU setting, and in particular the case wherein survival is felt to be impossible, is a less difficult step for the neonatologist than for the PICU physician. It must be acknowledged, however, that despite a perception of ethical equivalence, withholding intubation and assisted ventilation in the DR may nevertheless feel very different to staff, and more importantly to parents, compared with the NICU. A perception of acceptability of unilateral DNAR in the DR does not necessarily yield the same sense in the NICU. Thus, it is a significant finding that most responding neonatologists found it acceptable in the NICU under certain circumstances.

Another potential explanation of a possible difference in approaches in the NICU and PICU could relate to the difference in the psychological impact of managing newborns exclusively, compared with also managing older children. This is certainly a complex subject, and clearly beyond the scope of this essay, but may nevertheless play an important role in physicians' thinking. ¹¹ Finally, it is worth noting that in some of Morparia's vignettes the patients were old enough to have formed, and possibly expressed, opinions regarding resuscitation. This highlights another important difference in resuscitation decisions in these two very different settings.

Though the ethical analysis of unilateral DNAR was explored in greater detail in our earlier essay, at least a brief summary of some relevant arguments seems warranted. One argument in favour of the use of unilateral DNAR orders, for cases wherein survival is believed impossible, relates to the potential burdens to the patient of a procedure that appears to offer no significant benefit. This would include the risk of pain during the attempted resuscitation, and possibly during a period of protracted dying. This seems a violation of the child's right to mercy. That is, the right not to be made to undergo potentially painful interventions that offer no significant benefit to the patient. The needs of the parents, such as the need to believe all efforts were made to save their child, are also a valid concern, however, and it seems reasonable that they should often be weighed in the decision regarding DNAR status. Still, we would counsel consideration of the Kantian imperative not to make the child serve solely as a means to someone else's ends, even his parents. 12 Also, there is concern about the potential deception of parents when physicians attempt something that offers no chance of success.

In situations wherein survival is felt to be impossible, some have suggested a feigned attempt at resuscitation, sometimes

retes that referred to as a 'slow code' or 'Hollywood code,' with no real goal of restoring vital signs. 13 While we believe the motives of those who have advocated this approach are sometimes laudable (e.g., reducing the parents' suffering by sparing them the decision regarding DNAR status), we agree with those who suggest this is an unnecessary deception. Rather than feign an attempt to restore vital signs or stability, we have advocated for a unilateral DNAR decision coupled with compassionate explanation in certain extreme cases. 14 1.6 We believe that unilateral DNAR is a complex ethical question, with thoughtful and dedicated physicians coming down on both sides, and strong arguments to be made on both sides, and refer the reader to our earlier publication (DR)

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It is understandable that the number of those who considered unilateral DNAR permissible increased substantially when the chance of success went from 'unlikely' to 'impossible.' The imperfections of our prognostic abilities rightly loom large in this matter, ¹⁶ and it seems wise that we should require a high degree of confidence in any perceived prognosis before we permit it to limit the options offered to parents. It is not surprising that increased confidence in the prognosis would yield a greater number of physicians willing to decide or act based upon that prognosis.

While a clear majority of responding neonatologists found a unilateral decision ethically permissible when survival was not felt to be possible, only half would actually choose to enact DNAR without parental approval. There are, for nearly all of us, things that we consider ethically permissible, but that we ourselves would not choose to do. With many ethical questions, there are commonly two separate thresholds: first, is it ethically permissible, and second (a higher threshold), would you do it. Put another way, there is often a lower threshold for what is permissible than for

Box 2 Key, considerations regarding unilateral Do Not Attempt Resuscitation (DNAR) orders

Physicians do not and should not, have an ethical obligation to provide treatment that offers no benefit to the patient. Rather, the obligation is to compassionately discuss the situation, reasonable options and what will be done

Asking parents to approve a DNAR order when death in the near future is inevitable may place an unnecessary and potentially significant burden on them

Performing cardiopulmonary resuscitation that offers virtually no chance of restoring vital signs may benefit the family in some circumstances; such as providing a desired ritual or giving them the feeling that everything was tried. It is controversial whether this justifies the potential hams to the patient, such as pain and indignity.

A unilateral DNAR order by the physician based on predicted disability risks inappropriately placing the values of the physician regarding quality of life over those of the patient or parents. Thus, unilateral decisions regarding DNAR status should generally be limited to cases of unavoidable imminent death, and perhaps the most extreme cases of poor quality of life, after confirmation of the prognosis and advisability of DNAR with colleagues.

The law regarding unliateral DNAR orders varies among states, and physicians should be familiar with the law where they practise

Source: Adapted from Blinded.

what is advisable. This is also true for many medical decisions. A given option may be something one might find permissible for any physician to do, but not necessarily the therapeutic path he/she would choose to take. And so it might be with a unilateral DNAR order; for some of the respondents, it may have reached the lower threshold of permissibility, though they themselves would not do it, nor recommend it to a colleague.

The discrepancy between what some neonatologists consider acceptable, and what they would actually do, should also be considered in light of the professional climate in American medicine. It has been reported that physicians in the USA commonly initiate and continue treatment until it is virtually certain that the patient will die, taking a 'waiting for near certainty' approach to end of life. To Comfort or familiarity with this approach, coupled with fear of medical uncertainty, and perhaps also fear of accusations of medical neglect and/or litigation, might further explain a physician's refuetance to enter a unilateral DNAR order into the medical record, even when he or she perceives that to do so would be acceptable. For some, it might amount to the conclusion that, "It would be ethically permissible to do it, but personally I would not take the risk."

The majority of respondents did not consider a unilateral DNAR decision based solely on poor neurological prognosis to be permissible, which was consistent with ethical arguments previously presented.1 Determining that an infant's neurological prognosis and predicted quality of life are too poor to wartant CPR, without seeking parental agreement, requires giving precedence not only to the physician's medical judgement, but also to the physician's value judgements. It must be acknowledged that physicians' prognostications about the level of disability are sometimes wrong, and that quality of life assessments are subjective. 18 19 Thus, we share the intuition expressed by most neonatologists in this study, that a DNAR order without parental agreement, based solely on predicted neurological disability, would be inappropriate in nearly all cases. However, there may be extreme examples of neurological disability, not covered by these vignettes, for which a unilateral DNAR order would be considered acceptable to many neonatologists and others. Current debate regarding resuscitation for patients with Trisomy 13 or 18 may, at least in part, be tied to this question.

Vignette 3 concerned a child who, due to a grim neurological prognosis from an incurable underlying disorder, had been judged incligible for potentially life-saving cardiothoracic (CT) surgery. The intent with this case was to query the opinion of neonatologists regarding unilateral DNAR orders when other important treatment is being been withheld. A majority of neonatologists (57%) believe a unilateral DNAR order would be permissible, though far fewer (37%) would enact such an order in this case. Interestingly, far more respondents felt the CT surgeon was justified in making a unilateral refusal regarding surgery, compared with those who felt it permissible for the neonatologist to make such a unilateral decision regarding resuscitation in this case (81% vs 57%).

The disconnect between what the respondents felt was permissible for the CT surgeon and neonatologist may be explained in part by the fact that the surgery is far more involved, requiring more time, effort and utilisation of resources, as well as being more invasive. Another possible factor is the more immediate result of the decision. While both refusals could eventually result in death, a death related to a refusal to operate may often be less immediate than the death that results from a refusal to perform CPR. There may also be very different perceptions regarding death associated with the surgery compared with attempted CPR, the former more likely to have negative

implications and/or consequences for the physician. Lastly, it may be, in the minds of some, that there is something fundamentally different, and more obligatory, about CPR compared with other treatments. This perceived difference could make CPR, for many, a notable exception to the widely held notion within the medical profession that a physician is not obligated to offer or attempt a treatment that cannot work. The ethical justification for that perceived exception, however, is not immediately obvious. This disconnect should be studied further, but acceptance of refusal by the neonatologist or the surgeon may ultimately both be rooted, at least in part, in the belief that the physician retains the moral authority to make some decisions about the purposes to which his or her skills can be put.²⁰

More experienced physicians were less likely than their less experienced peers to make a unilateral decision regarding resuscitation when survival was felt to be impossible, though a majority of them still considered it acceptable. This difference might be explained in part by having greater experience with, and appreciation for, the reality documented by Meadow et al, that physicians and others in the NICU are not particularly good at predicting which patients will die. ¹⁸ Also, while this survey did not ask when the respondents began practising, some of the respondents in the >1.5 years in practice category may have been in medical school, residency or fellowship during times of landmark ethical cases in paediatrics. Perhaps being educated in the environment of the Baby Doe regulations, and the ethical upheaval that ensued, leads to a greater reluctance to make resuscitation decisions unilaterally.

This survey study has several limitations. The response rate of 16% is low, and thus these data may not accurately represent the views of most American neonatologists. There may have been a selection bias, in that those favouring one viewpoint or another might be more likely to respond to a survey such as this. It is also possible that neonatologists who are members of the American Academy of Pediatrics (AAP) perinaral section are not truly representative of the profession. While every attempt was made to make the vignettes as realistic as possible, they are very brief snapshots or what are often far more complicated situations, and thus run the risk of oversimplification. For clinical scenarios wherein the decision was already made for a unilateral DNAR order, respondents may have been subject to a status quo bias in decision making, thus going along with information/decision already presented.21 For many, a judgement regarding unilateral DNAR might be influenced by factors that were not discussed, such as parental preferences, religion and family situation.

CONCLUSION

Most neonatologists surveyed believed unilateral DNAR decisions made by physicians are ethically permissible when survival is felt by the physician to be unlikely, and an even greater majority believed it permissible when survival was felt to be impossible. However, most did not perceive unilateral DNAR orders as being permissible when based solely on poor prognosis regarding disability. This suggests that unilateral DNAR decisions, traditionally and currently sometimes made in the DR, are also sometimes being made in the NICU. Ethical justification for such decisions may be based on concern for unnecessary burden to the child, but often hinge on the degree of certainty regarding prognosis The reluctance to unilaterally withhold potentially life-saving resuscitation, based solely on neurological prognosis, may be justified by an appreciation of the inherent subjectivity of value judgements regarding disability and quality of life. Whether the setting is poor prognosis for survival or poor neurological

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prognosis, a significant number of neonatologists come down on each side of the question of unilateral DNAR.

Contributors PDM: conceptualised and designed the study, drafted the initial manuscript and approved the final manuscript as submitted. DE: carried out the data analysis and approved the final manuscript as submitted. MRM: reviewed and revised the manuscript, and approved the final manuscript as submitted.

Competing interests None declared.

Ethics approval Institutional review board approval was granted by Yale University.

Provenance and peer review Not commissioned; externally peer reviewed.

REFERENCES

- Mercurio MR, Murray PD, Gross J. Unilateral "do not attempt resuscitation" orders: the pros. the cons, and a proposed approach, Pediatrics 2014;133 (Suppl 1):
- American Medical Association, Council on Ethical and Judicial Affairs. Report of the council on ethical and judicial affairs, code of medical ethics. IAMA 1999;281:937-41.
- 3 Ardagh M. Futility has no utility in resuscitation medicine. J Med Ethics 2000;26:396~9.
- Younger SJ. Who defines futility. JAMA 1988;260(14):2094-5.
- Bell EF, Stark AR, Adamkin DH, et al., American Academy of Pediatrics, Committee on Fetus and Newborn. Noninitiation or withdrawal of intensive care for high-risk newborns. Pediatrics 2007;119:401-3.
- Mercurio MR. Physicians' refusal to resuscitate at borderline gestational age. J Perinatel 2005;25:685-9.
- Periman JM, Wyllie J, Kattwinkel J, et al. American Academy of Pediatrics, Special Report- Neonatal Resuscitation; 2010 International Consensus on Cardiopulmonary

- 3-1 Filed 04/28/16 Page 15 of 18 Resuscitation and Emergency Cardiovascular Care Science With Treatment Recommendations. Pediatrics 2010;126:e1319-44.
- Harrison C. Canadian Paediatric Society, Position Statement- treatment decisions regarding infants, children, and adolescents. Paediatr Child Health 2004;9:99-103.
- Brazier M, Krebs J, Hepple B, et al. Criucal care decisions in fetal and neonatal medicine: ethical issues. Nuffield Bioethics 2006.
- Morparia K, Dickerman M, Hoehn S, Futility: unilateral decision making is not the default for pediatric intensivists. Pedaltr Crit Care Med 2012;13:e5.
- Janvier A, Mercurio MR, Saving vs creating: perceptions of intensive care at different ages and the potential for injustice. J Perinatal 2013;33:333-5.
- Lechner S, Kantian ethics. Kantian Rev 2011;16:141-50.
- Lantos JD, Meadows WL. Should the "slow code" be resuscitated? Am J Bioeth 2011:11:8-12.
- Mercurio MR. Faking it: unnecessary deceptions and the slow code. Am J Bloeth 2011:11:17-18.
- Kon AA. Informed non-dissent, A better option than slow codes when families 15 cannot say "Let her die". Am J Bioeth 2011;11:22-3.
- Meadow W, Frain L, Ren Y, et al. Serial assessment of mortality in the neonatal intensive care unit by algorithm and intuition: certainty, uncertainty, and informed consent, Pediatrics 2002;109:878-86.
- Rhoden NK. Treating Baby Doe: the ethics of uncertainty, Hastings Cen Rep 17 1986;16:34-42.
- Koogler TK, Wilfond BS, Ross LF. Lethal language, lethal decisions, Hastings Cen 18 Rep 2003;33:37-41.
- Kipnis K. Harm and uncertainty in newborn intensive care. Theor Med Bioeth 19 2007;28:393-412.
- Tomlinson T, Brody H. Futility and the ethics of resuscitation. JAMA 1990;264 (10):1276-80.
- Samuelson W, Zeckhauser R, Status quo bias in decision making. J Risk Uncertain 1988;1:7-59.

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In what circumstances will a neonatologist



decide a patient is not a resuscitation candidate?

Peter Daniel Murray, Denise Esserman and Mark Randolph Mercurio

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Jonee Fonseca 1 Mother of Israel Stinson Address 2 3 Telephone withheld for privacy but provided to Court and Respondent 4 5 6 IN THE SUPERIOR COURT OF CALIFORNIA 7 IN AND FOR THE COUNTY OF PLACER 8 UNLIMITED CIVIL JURISDICTION 9 10 Israel Stinson, a minor, by Jonee Fonseca his Case No. 11 mother 12 DECLARATION OF JONEE FONSECA IN Petitioner, SUPPORT OF EX-PARTE PETITION FOR 13 TEMPORARY RESTRAINING ORDER/INJUNCTION: REQUEST FOR V. 14 ORDER OF INDENDENT 15 NEUROLOGICAL EXAM; REQUEST FOR UC Davis Children's Hospital; Kaiser Permanente Roseville Medical Center – ORDER TO MAINTIN LEVEL OF 16 Women and Children's Center. MEDICAL CARE 17 Respondent. 18 19 20 21 I, Jonee Fonseca, declare that I am the mother of petitioner Israel Stinson. 22 23 1. On April 1, 2016 I took Israel to Mercy Hospital with symptoms of an asthma attack. The 24 Emergency room examined him, placed him on a breathing machine, and he underwent 25 x-rays. Shortly thereafter he began shivering, his lips turned purple, eyes rolled back and 26 lost consciousness. He had an intubation performed on him. Doctors then told me they 27 28

- had to transfer Israel to UC Davis because they did not have a pediatric unit. HE was then taken to UC Davis via ambulance and admitted to the pediatric intensive care unit.
- 2. The next day, the tube was removed from Israel at UC Davis. The respiratory therapist said that Israel was stable and that they could possibly discharge him the following day, Sunday April 3.
- 3. The doctors at UC Davis put Israel on albuterol for one hour, and then wanted to take him off albuterol for an hour. About 30 minutes later while off the albuterol, I noticed that he began to wheeze and have issues breathing. The nurse came back in and put Israel on the albuterol machine. Within a few minutes the monitor started beeping. The nurse came in and repositioned the mask on Israel, then left the room.
- 4. Within minutes of the nurse leaving the room, Israel started to shiver and went limp in my arms. I pressed the nurses' button, and screamed for help, but no one came to the room. A different nurse came in, and I asked to see a doctor.
- 5. The doctor, Dr. Meteev came to the room and said she did not want to intubate Israel to see if he could breathe on his own without the tube. Israel was not breathing on his own. I had to leave the room to compose myself.
- 6. When I came back into the room five minutes later, the doctors were performing CPR on Israel. The doctors dismissed me from the room again while they performed CPR for the next forty (40) minutes.
- 7. After CPR was performed, Dr. Meteev told me that Israel was going to make it and that he would be put on an ECMO to support his heath and lungs.

- 8. Dr. Meteev also told me that Israel might have a blockage in his right lung because he was not able to receive any oxygen. A pulmonologist checked Israel's right lung, and he did not have any blockage.
- 9. Dr. Meteev then indicated that there was a possibility Israel will have brain damage. HE was sedated twice due to this blood pressure being high, and was placed on an ECMO machine and ventilator machine.
- 10. On Sunday April 3, 2016, A brain test was conducted on Israel to determine possibility of brain damage while he was hooked up to the ECMO machine. The test involved poking his eye with a Q-tip, banging on his knee, flashing a light in his eye, flushing water down his ear, and putting a stick down his throat to check his gag reflexes. On April 4, 2016, the same tests were performed when he was taken of the ECMO machine.
- 11. On April 6, 2016 Israel was taken off the ECMO machine because his hearth and lungs were functioning on their own. However, the next day, a radioactive test was performed to determine blood flow to the brain.
- 12. I begged for an MRI and CT scan to be done on Israel before the third and final doctor performed the test. This was done on April 10, 2016. These results still have not been given to me, and I've been told that the results are only "preliminary."
- 13. On April 11, 2016, Israel was transferred via ambulance from UC Davis to Kaiser Permanente Women and Children's Medical Center in Rosveille. Upon our arrival at Kaiser, another reflex test was done, in addition to an apnea test. On April 14, 2016, an additional reflex test was done.
- 14. I am a Christian and believe in the healing power of God. I do not want Israel pulled off life support. Kaiser has said that they have the right to remove Israel from life support.

- 15. I am hereby asking that Kaiser Permanente Roseville Medical Center be prevented from removing my son, Israel Stinson, from his ventilator.
- 16. If Kaiser removes Israel from a respirator and he stops breathing then they will have ended his life as well as their responsibility to provide his future care for the harm their negligence caused. For this reason I hereby request that an independent examination be performed, including the use of an EEG and a cerebral blood flow study.
- 17. I also request that Kaiser Permanente Roseville Medical Center be ordered to continue to provide such care and treatment to Israel that is necessary to maintain his physical health and promote any opportunity for healing and recovery of his brain and body.

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct. Executed on April , 2016, at Roseville, California.

Jonee Fonseca