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SUPERIOR COURT OF THE STATE OF CALIFORNIA

FOR THE COUNTY OF ALAMEDA

LATASHA NAILAH SPEARS WINKFIELD; MARVIN WINKFIELD; SANDRA CHATMAN; and JAHI McMATH, a minor, by and through her Guardian ad Litem, LATASHA NAILAH SPEARS WINKFIELD,,

Plaintiffs,

v.

FREDERICK S. ROSEN, M.D.; UCSF BENIOFF CHILDREN'S HOSPITAL OAKLAND (formerly Children's Hospital & Research Center at Oakland); MILTON McMATH, a nominal defendant, and DOES 1 THROUGH 100,

Defendants.

Case No. RG15760730 FAX FILE

Assigned for All Purposes to the Hon. Stephen Pulido , Dept. 16

DECLARATION OF D. ALAN SHEWMON, M.D.

Complaint Filed: November 1, 2013

DECLARATION OF D. ALAN SHEWMON, M.D.

I, D. Alan Shewmon, declare:

1. I have been an academic pediatric neurologist since 1981 and am currently Professor Emeritus of Pediatrics and Neurology at the David Geffen School of Medicine at UCLA. My professional training includes a bachelor's degree from Harvard College in 1971, a medical degree from New York University Medical School in 1975, two years of pediatric residency at San Francisco Children's Hospital (now California Pacific Medical Center), three years of neurology residency at Loyola University Chicago Stritch School of Medicine, and one year of fellowship at UCLA in developmental disabilities and mental retardation. I am triply board certified: in Pediatrics, Neurology (with special competence in Child Neurology), and Clinical Neurophysiology. From 2003 to 2014 I was Chief of Neurology at Olive View-UCLA Medical Center, a county hospital affiliated with UCLA, and Vice-Chair of the Neurology Department at UCLA. Since retiring from county employment in 2014, I have remained clinically active, maintaining my clinic at Olive View-UCLA and consulting for five other hospitals in the Los Angeles area. I am a member in good standing of the American Academy of Neurology, the Child Neurology Society, the American Epilepsy Society, and other professional organizations detailed in my CV.

2. I have never charged for nor have I received any financial compensation from Jahi McMath's family or from their lawyers for my professional time reviewing the documentation and providing my expert opinions in this case. I have volunteered my time and effort out of a combination of humanitarian, ethical, academic and research interests. This declaration supplements my declaration dated December 10, 2014 filed in this case.

3. My two main areas of special expertise have been pediatric epilepsy and the interface between neurology and bioethics, particularly brain death and vegetative state. A rough estimate of the total number of brain death cases I have diagnosed in the course of my career, according to accepted medical standards, is probably between 150 and 200. My philosophical opinion about the concept of brain death (*vide infra*) has no impact on how I go about diagnosing brain death in day-to-day clinical situations.

4. My expertise in brain death is internationally recognized. Related to that specific topic alone, my CV lists 13 peer reviewed publications, 2 invited reviews, 1 book, 12 chapters, 36 invited lectures at the international level and 20 at the national level. Three of the peer-reviewed publications were given pride of place in their respective journal issues. One was the lead article in a major biostatistics journal. [1] Another was a feature article in the official journal of the American Academy of Neurology, [2] accompanied by an invited editorial [3] and selected for mention in the "Highlights" section. The entire October 2001 issue of *Journal of Medicine and Philosophy* was dedicated to commentaries on my lead article, none of which disputed my arguments and conclusion about brain death with respect to the biological organism as a whole. [4]

5. In the mid-1980s I was a member of the Child Neurology Society's Ethics Committee, when it was entrusted with the task of drafting the first diagnostic guidelines for brain death in children (predecessor of the 1987 Task Force guidelines [5]). I was a consultant for two Working Groups of the Pontifical Academy of Sciences on the determination of death in 1989 [6] and 2006 [7], and a member of the Task Force on Brain Death of the Pontifical Academy for Life (1997-98). I was on the Organizing and Scientific Committees for the 3rd and 4th International Symposia on Coma and Death in Havana (2000 and 2004), and together with the conference organizer I was co-editor of the book "Brain Death and Disorders of Consciousness." [8] In 2007 I was a consultant to the President's Council on Bioethics during the drafting phase of their White Paper on brain death. [9] In 2012 I was a consultant to the German Ethics Council in its deliberations on brain death.

A. Jahi McMath does not currently fulfill the accepted medical standards for brain death.

6. There is no question that in December 2013 at Oakland Children's Hospital, Jahi McMath fulfilled the widely accepted pediatric guidelines for determining brain death (hereinafter referred to simply as the Guidelines), [10-12] as well as the adult guidelines, [13] both regarded as the accepted medical standards. There is equally no question in my mind that she no longer does, for the single reason that the first of the "three cardinal findings in brain death" [14] –

coma, absence of brainstem reflexes, and apnea–is not fulfilled. Rather, she is intermittently responsive, placing her in the category of "minimally conscious state." [15, 16]

7. The change took place around the spring of 2014, when Jahi's family members began to suspect that she sometimes seemed to respond to command. When I first heard of this through the news media, I was as skeptical as everyone else, assuming that they were mistaking spinal reflexes or myoclonus (involuntary quick jerks) for voluntary movements. Because of my research interest in the phenomenon of chronic brain death, I contacted Jahi's family through her attorney, Christopher Dolan, and developed a rapport with them.

8. Realizing that no one was likely to believe them about Jahi's intermittent responsiveness, the family began making video recordings of what they believed to be motor responses to simple commands. They gradually formed the impression that Jahi's responsiveness tended to occur when her heart rate was above 80 beats per minute, and hardly ever when it was slower–suggesting the possibility of some sort of inner state differentiation, with responsiveness more likely during the more aroused state. Therefore, they tended to wait for occasions when her heart rate was over 80 to record command-response sessions.

9. The intermittency of the alleged responsiveness–as infrequent as weekly or less, sometimes more–creates a particular challenge to either disprove or verify, because the likelihood of Jahi being in a "responsive" state during a random examination is small. In fact, when I had the opportunity to examine her in person on December 2, 2014, it was one of her less "aroused" days, and she did not respond to command in my presence. (Neither did she exhibit any cranial nerve reflexes or breathe spontaneously over the ventilator–all consistent *at that moment* with continued fulfillment of the brain death Guidelines.)

10. This is why the video recordings, as crude and unsystematic as they are, represent the only way at present to decide whether Jahi is permanently comatose or in a minimally conscious state with intermittent responsiveness. During the time period from March 2014 through April 2016, Jahi's family entrusted me with a total of 49 distinct digital video files (not counting several duplicates with different file names), believed to constitute the entire collection of existing command-response videos. These have all been made available to the court and to the

expert consultants for the defense, who both cite them as among the material received [Nakagawa, p. 12; Schneider, p. 8] but make no other mention of them in their respective declarations. Every video file has been subjected to expert forensic video analysis and certified to contain no evidence of post-recording alteration.

11. File durations ranged from 13 to 732 seconds, with a median of 70 seconds. The videos contain 193 commands and 668 elementary movements (counting individual components of compound movements). Some movements, especially of the fingers, have the quality of myoclonus (quick involuntary jerks, almost certainly originating in the spinal cord). Judging from the sound track, most of the finger myoclonias were considered by family to be involuntary and of no interest. The movements that they interpreted as responses to command were for the most part slower, with durations ranging from around half a second to a few seconds for simple movements and over 10 seconds for more complex movements.

12. *Most of the non-myoclonic movements bear no resemblance to any kind of reflex or spontaneous spinal cord-generated movements ever reported to occur in spinal cord injury patients below the level of the lesion.* The repertoire of endogenous spinal cord-generated spontaneous movements (after resolution of spinal shock) includes: myoclonus (a brief, single twitch), clonus (a rhythmically repetitive, hyperactive muscle stretch reflex), muscle spasms including massive body spasms (often provoked by internal noxious stimuli such as constipation or a full bladder), alternating flexion-extension leg movements, periodic limb movements and restless legs syndrome. [17-30] The autonomous cord is not known among neurorehabilitation experts to generate any other type of spontaneous (or apparently spontaneous) movement. Jahi has manifested myoclonus, clonus, and massive spasms at various times, but only myoclonus (almost entirely of the fingers) and clonus occurred during the videos.

13. An obvious objection is that these videos could have been cherry-picked from a much larger set of recordings, and only the ones that supported the family's claim were released. They did, in fact, discard a number of videos in which no post-command movements occurred, until I asked them to keep and send everything. The set of 49 video files contains 5 with no

movements at all and a total of 38 commands followed by no movement of the requested body part.

14. There are no videos of pure baseline without any command, at times when family might have suspected responsiveness (on the basis of heart rate over 80) and could have attempted a command-response trial but did not for the sake of establishing a baseline. If all of Jahi's movements were of endogenous spinal origin and the "responses" were mere temporal coincidences relative to commands, it is reasonable to assume that each body part had a characteristic average rate on days when family suspected her to be most likely "responsive" (heart rate above 80) and made a video (and a lower rate on days when they considered her unresponsive and didn't bother). Therefore, a reasonable estimate of baseline non-myoclonic movement frequency for each body part can be inferred from the periods when that particular body part was not the subject of a command, averaged across all videos.

15. It would be completely implausible if, on a given day frequent endogenous movements occurred in only the left arm, for example, while the other body parts had only rare movements, so the family decided to make a video demonstrating "responsiveness" to left arm commands; and then on another day only the right foot had frequent endogenous movements while all other body parts had rare movements, so they decided to make a video on that day demonstrating "responsiveness" to right foot commands; etc. On days with heart rate above 80, when non-myoclonic movements are more likely to occur, it is much more plausible that the average rate for each body part would be relatively homogenous from day to day, so that the average across the whole set of videos during non-command periods should be a reasonable approximation of the baseline movement frequency for each body part.

16. Careful examination of the video data leads to the following conclusions about the non-myoclonic movements.

17. (1) The baseline frequency of non-myoclonic movements in a given body part is very low, whereas it is much higher during periods of request for movement of that body part. It is therefore extraordinarily unlikely that the movements during command times arose from the same process as the baseline movements. As a related observation, movements occur much

sooner after commands than would be expected on the basis of random occurrence at baseline frequency.

18. (2) There is a very strong correspondence between the body part requested and the next body part that moves. This cannot reasonably be explained by chance.

19. (3) There is a very strong correspondence between the laterality of the body part requested and the laterality of the next body part that moves. With thumb or finger commands, the camera was usually focused close-up on the expected hand. Therefore, this laterality effect is best demonstrated with those commands where both right and left sides were in camera range simultaneously for the body part commanded.

20. (4) Some videos show qualitative aspects indicative of more complex comprehension and volition.

21. For example, in "VIDEO0112.mp4," made on 3/17/14, Jahi's mother asks her to move her right hand, and 6 seconds later the right arm extends at the elbow, passively moving the right hand along with the forearm (total movement duration 4 seconds). Then mother asks her to move the left hand, and 12 seconds later there is a pair of slight lateral twitches of the left forearm (they resemble myoclonus, but similar movements of the left forearm never occurred during a total of 37 minutes of baseline time when no arm was commanded). Then mother asks her to move the left hand *harder*, and immediately there is another pair of lateral twitches of the left forearm, *stronger than before*.

22. In "jahi thumbs up.3gp," made on 10/30/2014, Jahi's aunt asks her to put her thumb up; 10 seconds later there is a slight myoclonic jerk of the left third finger and a pair of slight myoclonic flexion jerks of the left thumb. Her aunt tries to encourage her by saying, "I see you moving. Try to put it up," and a second later the left thumb makes a non-myoclonic (total duration 1 second) flexion movement, with simultaneous slight pronation of the left forearm and slight movement of the second finger toward thumb. The aunt says, "I see you trying, honey. You just moved your thumb. Can you put it *up*?" With a bit of further coaxing, 14 seconds later the left thumb extends *upward* with a non-myoclonic movement.

23. In "Jahi relax hand.mp4," filmed on 1/13/2015, Jahi's aunt had been asking her to move her thumb prior to the start of the video (by implication from the sound track, the first words of which were "I see you movin' it, Jahi. Could you put your thumb all the way up?") At 14 seconds into the video, between the words "thumb" and "all" of the repeat command, there is a large, slow flexion/opposition movement of the right thumb while the second and third fingers flex at the metacarpophalangeal joints. After praising Jahi, the aunt says *sotto voce* to someone else in the room at 27 seconds: "She's not relaxing her hand; she's still trying." Jahi's fingers and hand muscles are visibly tense on the video. Then the aunt says to Jahi: "*Relax*, girlie. Relax your fingers, Jahi." Four seconds after the first "Relax," the hand and fingers begin to visibly *relax*, gradually returning to their pre-movement position over the next 2 seconds.

24. In "20160224_the bad finger lol.mp4," Jahi's mother asks her to move her third finger, but without using the phrase "middle finger." Rather, the requests are made in terms of circumlocutions, such as: "Which finger is the 'bad' finger?" "Which finger would I move, if'n I get mad at somebody?" "Which finger is the 'f- you' finger?" "So when you get mad at somebody, which finger you 'posed to move?" Two seconds after the first question, the left middle finger flexes (non-myoclonic). One second after the second question, the left middle finger flexes with a velocity making it arguably a myoclonic jerk. Two seconds after the third question, the left middle finger does likewise again . Two seconds after the fourth question, the fifth finger makes a small myoclonic jerk. Mother says, "Not *that* one," and 4 seconds later the *third* finger makes a large, slow flexion (definitely not myoclonic). Even if the second and third trials are excluded as possibly involuntary myoclonus (they could also have been quick voluntary responses), the first and fourth trials involved slower, non-myoclonic movements (which never occurred during 29 minutes of non-commanded left third finger baseline), suggesting a *level of linguistic comprehension* more complex than the usual "move your X [body part]" type of command.

25. *Taken together, the video evidence indicates, beyond any reasonable doubt, that the slower, more deliberate-looking non-myoclonic movements are in fact not independent of the commands, ruling out some hitherto unknown type of spinal automatism. There is clearly a*

causal relationship, indicating that at the times the videos were made, Jahi was in a responsive state, capable of understanding a verbal command and barely capable of executing a simple motor response.

26. The obvious question is: How is this possible, given that on September 26, 2014 at University Hospital, her EEG was flat, suggesting absolute unconsciousness; her somatosensory evoked response test showed no response above the mid-cervical level, suggesting "loss of neurological brain pathway function above this level;" [Schneider declaration, p. 14, line 1] and her auditory evoked potential test showed no response, suggesting that "she has no auditory pathways." [Id. at p. 14, line 1] Dr. Schneider interprets the latter result as "establish[ing] to a reasonable degree of medical certainty that J. McMath cannot respond to verbal commands because she has no cerebral mechanism to hear sound." [Id. at p. 14, lines 6-7] I certainly agree that the tests would seem to imply these things, raising serious difficulties for reconciling them with the video evidence of intermittent responsiveness to commands.

27. I do not pretend to know the explanation for the apparent discrepancies. But instead of concluding that "It is a medical impossibility that J. McMath is moving in response to verbal commands," [Schneider declaration, p. 14, lines 2-3] regardless what the videos show, in a matter as important as life or death I prefer to give the benefit of the doubt to the behavioral evidence of responsiveness, which seems incontrovertible, and entertain the possibility that these tests may not imply as much about the functioning of a severely damaged brain as we usually assume. The following are some possible alternative explanations for the test results.

28. But first, let us put to rest a particular complaint regarding these tests, repeated by Drs. Nakagawa and Schneider. Dr. Nakagawa states that "The tests performed on McMath at University Hospital on September [MRI, MRA, MRV, evoked potentials] are not accepted, validated ancillary studies and do not meet accepted diagnostic criteria for determining brain death (i.e., the Guidelines) and are not a substitute for the accepted medical standards." [Nakagawa declaration, p. 22, lines 7-10] Dr. Schneider states the same: "Although these tests are not the accepted diagnostic criteria for determining brain death, ..." [Schneider declaration, p. 11, lines 15-16] "Brain MRI and MR angiography are not validated tests to assess brain death.

The Guidelines state: 'MRI-MR angiography, and perfusion MRI imaging have not been studies sufficiently nor validated in infants and children and cannot be recommended as ancillary studies to assist with the determination of brain death in children at this time.' (Ex. B, p. e729) The above accepted medical standards for diagnosing pediatric brain death have not been applied to J. McMath since Dr. Paul Fisher's examination performed at Children's Hospital Oakland on December 23, 2013." [Schneider declaration, p. 13, lines 8-14]

29. Their insistence on this point is a *non sequitur*. The tests were not done in order to "determin[e] brain death" or to "substitute for the accepted medical standards," but to evaluate, out of interest, the structure and electrophysiological functioning of Jahi's brain 9 months after the uncontroverted diagnosis of brain death according to the Guidelines. Regarding the electrophysiological tests, I agree completely with Dr. Schneider that "the results are consistent with J. McMath's diagnosis of brain death made in December 2013," and that "None of the results would cause a reputable expert in pediatric or adult brain death to question or reconsider the accepted brain death assessments of Dr. Robin Shanahan, Dr. Robert Heidersbach and Dr. Paul Fisher performed in December 2013 at Children's Hospital Oakland." [Schneider declaration, p. 11, lines 17-20] But they are also "consistent with" the possibility that Jahi is *currently not* brain dead, even though that would go against the supposed infallibility of the Guidelines.

30. First of all, the MRI scan on September 26, 2014 showed that Jahi's brain had (and presumably still has) a surprising amount of preserved structure for a brain that was supposedly totally destroyed 9 months previously. Brain scans on three cases of chronic brain death that I have studied showed complete liquefactive necrosis (destruction) of the entire brain months after the onset of brain death. In one case, the first MRI scan was performed 13.9 years into brain death; an eventual autopsy showed no identifiable brain tissue. [31] The other two had scans performed closer to the same post-brain-death time frame as Jahi's MRI scan. One was a 15-year-old girl who became brain dead from a malignant brain tumor; a CT scan 10 months into brain death showed replacement of most of the brain, especially the cerebral hemispheres, by

fluid.[1] The other was a boy who became brain dead at age 13 months from an overwhelming presumed viral infection, whose MRI 31 days later showed advanced, widespread necrotic changes; the next neuroimaging was a CT scan 1.7 years into brain death, showing the skull to be filled with disorganized fluids and membranes, without identifiable brain structures.

31. If Jahi's MRI scan had shown similar findings, she could not possibly be intermittently responsive, there would be no videos showing what these videos show, and I would not be making this declaration. As it is, Jahi's MRI revealed a surprising extent of relatively preserved brain tissue (albeit with abnormal signal properties). This tells us in retrospect that in December 2013 when she was diagnosed brain dead, the lack of brain function was due more to *low* rather than *absent* blood flow – low enough to abolish neuronal function but not low enough to cause necrosis (tissue destruction) in much of the brain. This range of cerebral blood flow is called the "ischemic penumbra." The goal of stroke therapy is to rescue the (potentially reversibly) nonfunctioning brain tissue in the ischemic penumbra, since the necrotic core of the stroke is already a lost cause. The Brazilian neurologist Coimbra insightfully pointed out that as intracranial blood flow decreases from normal to zero during the pathophysiological vicious cycle leading to brain death, it necessarily passes through a stage of *global* ischemic penumbra. [32] If the brain's nonfunction is due to ischemic penumbra, all elements of the standard diagnostic Guidelines will be fulfilled, but there is still the potential for recovery of function because the brain tissue is still viable; therefore, the critical element of *irreversibility* in the statutory definition of death is not fulfilled.

32. I am convinced that Jahi's case proves Coimbra's thesis; her intracranial blood flow evidently did *not* progress all the way to zero, which would have resulted in necrosis of the entire brain, as in the three cases described above; much viable, though damaged, brain tissue remains. The fact that her radionuclide blood flow test on December 23, 2013 showed no identifiable brain blood flow proves only that the radionuclide test lacked the sensitivity to distinguish penumbra-level flow from no flow, contrary to the assertions of Dr. Nakagawa that it

[1] This and the previous case occurred prior to 1998 and were included in the data set of my article on chronic brain death.[2]

"conclusively demonstrates that there is no blood flow going to McMath's brain," [Nakagawa declaration, p. 19, lines 27-28; p. 23, lines 12-14] that "The cerebral blood flow performed on December 23, 2013 is conclusive evidence of McMath's death," [Id. at p. 24, lines 1-2] and that "The cerebral blood flow study performed on December 23, 2013, confirmed that McMath had no intracranial blood flow." [Id. at p. 24, lines 5-7] Dr. Schneider makes the same kind of assertion in his declaration: "The radionuclide cerebral blood study is diagnostic of J. McMath's brain death in that it conclusively demonstrates there is no blood flow going in J. McMath's brain." [Schneider declaration, p. 10, lines 9-11] These statements assume that radionuclide blood flow testing can distinguish no flow from penumbra-level flow in every part of the brain with 100% specificity for no flow–an assumption that has never been validated and is even unlikely, given that hypothalamic function as well as EEG activity can persist despite radionuclide tests or angiography showing apparently no blood flow to the brain. [33-38] Grigg et al. described two patients who met all clinical criteria for brain death short of an apnea test, who had flat EEGs and no apparent blood flow on radionuclide testing, yet breathed spontaneously during the apnea test. [39]

33. Jahi's MRI scan shows severe damage especially to the *brainstem*, with substantial parts of it missing (after the body's removal of necrotic tissue over the prior 9 months), most likely due to brainstem herniation around the time of diagnosis. Thus, it is not at all surprising that Jahi should still demonstrate absence of brainstem reflexes and apnea, and that her motor abilities are so severely limited. By contrast, consciousness, language processing, and initiation of voluntary movements are mediated by higher brain structures, which the MRI shows to be partially preserved.

34. Regarding the flat EEG, it is well known that this test reflects the electrical activity of only the part of the brain's cortical surface directly below the skull. Midline cortex (along the fissure separating the two hemispheres) and cortex at the base of the brain are not sampled by an EEG, nor are deep midline structures such as basal ganglia and thalamus, to say nothing of the brainstem. Thus, the EEG can be flat in cases of so-called "neocortical death"–an extreme form of persistent vegetative state, where patients are unresponsive but spontaneously

breathing and manifesting sleep-wake cycles due to an intact brainstem. [40, 41] It can also be flat, or nearly so, in cases of congenital absence of cortex known as hydranencephaly, despite behavioral evidence of adaptive, purposeful interaction with the environment (i.e., consciousness). [42] Such cases, together with animal data, suggest that in the context of severe cortical damage or even cortical absence, consciousness can still be mediated subcortically by deep midline structures such as thalamus and basal ganglia, and therefore not reflected in surface EEG activity. [43, 44]

35. In Jahi's case, there is the additional element of temporal variability. Most of the time she is not responsive, but sometimes she is. A random neurological examination would most likely find her unresponsive, with no clue as to the latent potential for responsiveness. What if her EEG behaved the same intermittent way? Who knows what her EEG might have looked like on days when the videos demonstrated responsiveness?

36. The somatosensory evoked response reveals function of the somatosensory pathways from peripheral nerve to cerebral cortex – and those pathways alone. It does not imply anything about the myriad other ascending and descending pathways between the brain and the spinal cord, such as motor pathways, which are located in different parts of the spinal cord and brainstem from the somatosensory pathways. It is not at all surprising, given the damage to the brainstem revealed on MRI, that there would be no somatosensory evoked responses above the cervical level. But that does not imply that the descending motor pathways are necessarily also nonfunctional. The brainstem is not completely destroyed, and it is totally conceivable that some descending motor pathways have survived. The somatosensory evoked response test, in and of itself, certainly does *not* establish a complete "loss of neurological brain pathway function above this [cervical] level," [Schneider declaration, p. 14, line 1] if the phrase "brain pathway" is intended to mean *all* pathways.

37. The brainstem auditory evoked response (BAER) test is harder to reconcile with responsiveness to commands. There was absence of all the main waves, including Wave I, which is generated peripherally by the acoustic nerve (transporting auditory signals from the cochlea to the brainstem). Wave I is often absent in brain death, in which case the absence of downstream

waves implies nothing about the integrity or lack thereof of the brainstem. Absence of Wave I ordinarily indicates a profound peripheral hearing deficit, but it does not necessarily indicate total deafness. [45, 46] Hearing can be preserved after acoustic neuroma surgery, despite absence of all waves on BAER. [47] Thus, it is possible that a partial disruption of the axons in the acoustic nerve can suffice to abolish the averaged evoked response but still permit sufficient transmission of auditory signals in the remaining axons to mediate hearing. Since BAER waves are computed averages of the brain's response to click stimuli, absence of Wave I (and consequently of subsequent waves) can also be due to imperfect synchrony of the signals within the acoustic nerve, not necessarily to a complete lack of signals. Instead of reasoning "Jahi's evoked potential test showed no waves; therefore, she absolutely cannot hear," it is preferable to reason "there is behavioral evidence that Jahi hears; therefore, there is something about the evoked potential test and the auditory pathways in her case that we do not completely understand."

38. Given the evidence of intermittent responsiveness, we should be all the more willing to remain agnostic regarding her inner state of mind during periods of unresponsivity, rather than automatically equate it with unconsciousness. Patients with severe brain damage can have many other reasons for unresponsiveness besides unconsciousness. Failure to appreciate or properly test for subtle signs of awareness results in a substantial incidence of misdiagnosis of the vegetative state on the part of even experienced neurologists. [48, 49] Recent advances in technology have revealed that even some "vegetative state" patients who are truly unresponsive can be inwardly conscious, understand what is said to them, and follow verbal commands with their minds. [50-56]

39. Not only seemingly "vegetative" patients can be inwardly aware, but also seemingly comatose patients, for example during general anesthesia, [57, 58] or cases like Zack Dunlap, who was diagnosed brain dead (whether the Guidelines were followed to the letter remains undocumented) and eventually made an essentially complete recovery; he claims to remember hearing the doctor declare him brain dead and being extremely upset about it.[2]

[2] http://www.today.com/news/pronounced-dead-man-takes-miraculous-turn-2D80555113

40. The brain has a remarkable capacity to reorganize itself over weeks to months after injury in order to maximize function – a phenomenon called "plasticity." The fact that it took several months before Jahi first showed signs of intermittent responsiveness is consistent with the time course of brain plasticity.

B. Jahi McMath does not currently meet California's statutory definition of death by neurologic criteria on additional grounds.

41. California's Health and Safety Code, Section 7180 states that "An individual who has sustained ... irreversible cessation of all functions of the entire brain, including the brain stem, is dead." The 1/7/14 Supplemental Declaration of Dr. Heidi Flori Opposing Petitioner's Request for Court Order Compelling Children's Hospital to Perform Tracheostomy and Insert Gastrointestinal Tube made a special point to underscore this definition by emphasizing the importance of *totality* of brain nonfunction in diagnosing brain death: "The diagnosis of death by neurological criteria is predicated not only on loss of higher cortical functions (emotions, voluntary movements, vision, etc.) but also on complete cessation of *all* brain functions, including those of the brain stem." (¶6, emphasis in original)

42. The accepted medical standards for diagnosing brain death in both adults and children (i.e., the Guidelines) give lip service to this definition, but in fact allow for certain functions of the brain to occur in patients meeting their criteria for "brain death." As mentioned above, the functions that the guidelines care about are of three "cardinal" categories: coma, cranial nerve reflexes, and apnea. But there are other categories of brain function, which proponents of diagnostic algorithms such as the Guidelines tend to write off as mere "activity" of a few residual neurons (nerve cells).

43. The distinction between "function" at the organ level and "activity" at the cellular level is valid and important, as explained by the 1981 President's Commission:

> After an organ has lost the ability to *function* within the organism, electrical and metabolic *activity* at the level of individual cells or even groups of cells may continue for a period of time. Unless this cellular activity is organized and directed, however, it cannot contribute to the operation of the organism as a

whole. Thus cellular activity alone is irrelevant in judging whether the organism, as opposed to its components, is 'dead.'" (p. 75, emphasis in original)

The Commission makes clear that what distinguishes a brain "function" from irrelevant neuronal "activity" is teleological. A function is not defined by how many cells carry it out (which could be very few), but by its role in the organism. Compared to the entire brain, the hypothalamus (a part of the brain that lies above and controls the pituitary gland, among many other functions) contains relatively few neurons, but so does the medulla. Hormonal control of fluid balance, for example, certainly "has significance for the organism as a whole" (p. 28) and "is organized and directed,... contribut[ing] to the operation of the organism as a whole," (p. 75) and therefore qualifies as a "function." If that control is mediated by a part of the brain–regardless how large or small a part–it rightly qualifies as a "brain function" and not merely "cellular activity."

44. In discussing the concept of "organism as a whole," Bernat seconds the President's Commission's distinction, listing some examples of "critical functions of the organism as a whole, which include: "(1) ... the autonomic control of circulation; (2) integrating functions that assure the homeostasis of the organism, such as ... neuroendocrine feedback loops, and temperature control." [59, pp. 257-8] Nevertheless, three paragraphs later he belittles one of the same functions if it occurs in the context of coma, absent brainstem reflexes, and apnea: "After brain death, ... some hypothalamic neuroendocrine activity of cells producing antidiuretic hormone can be assayed... In these instances, isolated nests of neurons have survived the global insult and continue to function independently. But because the neurological examination reveals an absence of clinical functions, these small, independent, multifocal areas of functioning cells do not contribute materially to the organism's clinical functions and thus do not count as evidence of functioning of the organism as a whole." [59, p. 258]

45. Bernat, Wijdicks and many others insist that the only functions that are important for distinguishing life from death are "clinical," meaning "those functions that clinicians can assess by bedside physical examination." [59, p. 258, 60] But this is completely *ad hoc*, contrary to the explanation that Bernat himself gave of "critical functions" of the organism as a whole (some of which are not assessed in the bedside physical examination), and contrary to the statutory

definition of death, which does not restrict the notion of "all brain functions" to the subset assessable by bedside examination. Besides, secretion of antiduretic hormone by the hypothalamus is even a "clinical" function, if one waits at the bedside long enough to observe the patient's urinary pattern or looks at the intake and output charting by nurses who have been at the bedside all day. So are blood pressure control and temperature maintenance "clinical functions" (vital signs are part of the bedside examination).

46. Nevertheless, the 1995 Practice Parameters for Determining Brain Death in Adults explicitly state that "Normal blood pressure without pharmacologic support" as well as "absence of diabetes insipidus" (i.e., maintenance of fluid balance through secretion of antiduretic hormone by the hypothalamus) are "compatible with the diagnosis of brain death." [14] The 2010 update specifies normal systolic blood pressure as a diagnostic prerequisite, stating "Hypotension... is common; vasopressors or vasopressin are often required," implying that they are not *always* required. [13] There is no requirement that temperature regulation be absent. (In fact, a core temperature ≥36.5 ^{0}C is a diagnostic prerequisite for the 1995 adult criteria, ≥36 ^{0}C for the 2010 update, and >35 ^{0}C for the pediatric Guidelines). Although temperature regulation is indeed faulty in most patients diagnosed as brain dead, some maintain normal body temperature without extraordinary warming measures beyond standard blankets. These functions are, by Bernat's account, "critical functions of the organism as a whole," and they are "brain functions" (parts of the hypothalamus and brainstem).[3] In fact, they are more critical to the organism as a whole than most, if not all, of the cranial nerve reflexes that the Guidelines require to be absent, and which are mediated by "nests of neurons" no more extensive than those in the hypothalamus.

47. This discrepancy between what the Guidelines diagnose and what the statutory definition of death specifies has been pointed out by many commentators. [61-68] Probably the main reason why the Guidelines focus so much on cranial nerve reflexes, to the exclusion of other types of clinically evident brain functions, is that they were drafted so as to correspond to the

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[3] Cardiovascular stability can in principle be maintained by spinal cord function, as the chronic brain death cases prove. But most brain death diagnoses are made in the very acute phase, when the spinal cord is relatively nonfunctional due to "spinal shock;" cardiovascular stability without pressor medication during that phase is therefore more likely attributable to brainstem function.

standard bedside neurological examination of a comatose patient. [69] If the brain death guidelines had been drafted by neuroendocrinologists, hypothalamic functions might well have been included in the list of brain functions required to be absent; and if they had been drafted by neurocardiologists, autonomic control of heart rate and blood pressure might well have been included among the brainstem functions required to be absent.

48. I shall expand briefly on neuroendocrine functions, because they are particularly relevant in Jahi's case. They frequently persist in patients who fulfill the standard diagnostic criteria for brain death. The most externally obvious neuroendocrine function commonly encountered in clinically diagnosed (but not statutorily defined) brain death is regulation of fluid balance through secretion of antidiuretic hormone (vasopressin) by the posterior pituitary gland, which is an extension of the hypothalamus. Absence of this hypothalamic function is manifested by a massive outpouring of dilute urine, a condition called diabetes insipidus. The reported incidence of preservation of this brain function (i.e. lack of diabetes insipidus) in brain death varies widely, but the average is around one-third of cases. [34, 70-76] The 1995 adult guidelines explicitly state that absence of diabetes insipidus is compatible with brain death, in flat contradiction to the statutory definition. [14, 77, p. 1007] The 2010 adult update [13] and the 2011 pediatric update [10-12] do not specifically mention diabetes insipidus, implicitly continuing to endorse the 1995 compatibility statement.

49. Regulation of anterior pituitary hormones by the hypothalamus is less clinically obvious than the presence or absence of diabetes insipidus, but it is a no less physiologically relevant *brain function* (actually multiple brain functions, one for each hormone regulated). [34-37, 71, 72, 78, 79] This includes normal levels of the sex hormones involved in puberty and menstruation. [35, 36, 72, 80] Thus, the statement by Dr. Schneider in his declaration–that in brain death "Hormones normally secreted by the brain [thyroid, adrenocorticoid, vasopressin] have to be externally supplied" [Schneider declaration, p. 6, lines 20-21]–is erroneous as a generalization.

50. Jahi McMath has diabetes insipidus, which is treated with hormone replacement. But she has evidence of different hypothalamic functions, namely puberty and menstruation. Menstruation occurred twice at St. Peter's hospital (physician progress notes, 8/6/14, 8/7/14, and

8/9/14, mentioning menstruation at that time and "a few months" prior) and a third time in her apartment (nursing notes, 9/9/14). She has also had development of pubic and axillary hair and breast enlargement since becoming brain dead. Neither the adult nor pediatric brain death Guidelines make any mention of puberty or menstruation, but clearly these are evidence of hypothalamic brain function, in contradiction to California's statutory definition of death. Corpses do not menstruate or develop sexually.

51. Jahi's body certainly functions biologically as a unified living organism, severely disabled and dependent on support to be sure. Loss of integrative unity was the rationale for why the 1981 President's Commission considered brain death to be death, and why the Commission felt confident in drafting the Uniform Determination of Death Act, after which most state death statutes (including California's) are modeled. It is also why the physicians at Oakland Children's hospital in December 2013-January 2014, and many other physician commentators at the time, were so sure that the diagnosis of brain death was correct in Jahi's case, not only because she fulfilled the diagnostic Guidelines but also because her biological organism was showing signs of dis-integration, as artificially maintained corpses necessarily do.

52. The 1/7/14 Supplemental Declaration of Dr. Heidi Flori nicely summarized these signs. It is worth quoting at length, in light of how Jahi's subsequent course defied all predictions of what must happen to dead bodies maintained indefinitely on ventilators:

> "6.... The brain stem provides vital regulatory control for critical bodily functions such as maintenance of heart rate, temperature, and respiratory effort, as well as regulation of nerve impulses that adjust the tone of blood vessels and nerves throughout the body. Therefore, the body of Ms. McMath, unlike the bodies of those patients with severe brain injury but with retained brain stem reflexes (including Terry Schiavo and Ariel Sharon), simply cannot regulate these life-sustaining functions over time.
>
> 7. The inability of Ms. McMath's body to regulate life-sustaining functions is already being demonstrated in many ways, including as follows:

a. She has not had evidence of bowel functioning (sounds) for weeks. Yesterday (January 2), she passed some stool that was clinically consistent with defecation of the tissues lining the bowel (i.e., her body is sloughing her gut). In living persons, absence of bowel sounds and sloughing of gut materials are both indications that enteral nutrition, which would occur through the g-tube being proposed, may be deleterious, particularly where, as here, there has been prior cardiopulmonary arrest and regulation of blood flow to the gut has been or continues to be compromised.

b. Although the medical team has done an excellent job of maintaining the body's external appearance (the hair is done, nails manicured, etc.), the tissues beneath the skin (subcutaneous tissues and muscles) are showing gradual signs of deterioration including change in skin "turgor" (in essence, its elasticity) and increase in muscle contraction (due to the loss of nervous system regulation).

c. The body also does not exhibit airway protective reflexes such as cough which are initiated by the brainstem. Although we are applying inhaled therapy twice daily to improve the body's "pulmonary toilet" (its clearance of pulmonary respiratory secretions), its secretions are continuing to change adversely with time. They are now more malodorous, changed in color (sometimes tan, creamy or bloody) and thicker in consistency.

d. Without nervous system control to adjust blood vessel tone with changes in body movement (as would normally need to occur to allow living persons to move form lying to sitting and sitting to standing), the body occasionally exhibits precipitous, although so far temporary, changes in blood pressure and oxygenation levels when staff are moving the torso up or down or side to side in order to complete daily care routines.

e. The body is unable to regulate temperature. Blankets are needed to maintain a temperature of greater than 35 degrees Celsius (95 degrees Fahrenheit).

f. Finally, the body has had gradually deteriorating blood pressures over the last three weeks, with blood pressures often half of what they were at the time Ms. McMath was first declared deceased. This again, is a testament to the body's long post-mortem course.

8. The medical team and I believe that additional and more dramatic signs of the body's deterioration will continue to manifest over time regardless of any procedures and regardless of any heroic measures that any facility in the country might attempt. This deterioration became inevitable the moment she died. Mechanical support and other measures taken to maintain an illusion of life where none exists cannot maintain that illusion indefinitely.

9. The additional medical interventions Petitioner proposes are unprecedented. They simply will not being her back to life nor enable others to do so. **Nor can they correct or even improve the above-described manifestations of the post-mortem deterioration of Ms. McMath's body.** Indeed, such measures may well be counterproductive, perhaps even resulting in expedited cardiopulmonary cessation." (emphasis added)

53. Every other physician commentator at the time seconded this opinion, as the news media documented. To take just one example:

"The bodies of brain dead patients kept on ventilators gradually deteriorate, eventually causing blood pressure to plummet and the heart to stop, said Dr. Paul Vespa, director of neurocritical care at the University of California, Los Angeles, who has no role in McMath's care. The process usually takes only days but can sometimes continue for months, medical experts say." [81]

54. Thus, Jahi's deterioration in late December 2013 and early January 2014 was held up as proof that she was most certainly a corpse being artificially maintained with the appearance of life. What then happened was that, upon transfer to St. Peter's Hospital in New Jersey, she received the tracheostomy and gastrostomy feeding tube that were refused in Oakland. She received the enteral feedings that her gut was supposedly unable to handle and that would only

be deleterious. With proper nutrition and other treatments appropriate for a patient requiring intensive care, her intestines healed, her skin turgor and pulmonary status recovered to normal, and she regained spontaneous maintenance of blood pressure without pressor medications. She still requires blankets to maintain temperature, but for the past 3+ years she has remained remarkably healthy, apart from being severely neurologically disabled. Most of that time she has not even been in a hospital, but in an apartment with the assistance of nothing more than a ventilator, excellent nursing care, hormone supplementation, and nutrition. Such recovery from impending multisystem failure and such improvement in overall health, as Jahi exhibited in the early months of 2014, is not possible for a ventilated corpse.

55. Dr. Schneider is certainly correct that "There is absolutely no medical possibility that J. McMath has recovered, or will someday recover, from death." [declaration, p. 14, lines 10-11] Short of biblical miracles, there is, by definition, absolutely no possibility that *anyone* can recover from death. What the above lines of evidence and reasoning show is rather that Jahi McMath was never truly dead, even though she fulfilled the accepted medical criteria for death in December 2013. She exhibited no brain function at the time, but the cessation of at least two functions–consciousness and hypothalamic regulation of menstruation and sexual development–has proved *not* to be *irreversible*. Hence she represents an example of a false positive (erroneous) diagnosis of brain death following the Guidelines.

56. The Guidelines permit the persistence of some brain functions (neuroendocrine, autonomic); therefore, they do not establish cessation of *all* brain functions, as California's statutory definition of death requires. Moreover, Jahi's case demonstrates that neither do they establish *irreversibility* of cessation of function, given that there is evidence, **to a reasonable degree of medical certainty**, of return of consciousness intermittently and recovery of some hypothalamic function.

57. Jahi McMath is a living, severely disabled young lady, who currently fulfills neither the standard diagnostic Guidelines for brain death nor California's statutory definition of death. At the very least, in a matter of life versus death, the compelling evidence of responsiveness to commands and of puberty warrants giving life the benefit of the doubt.

C. Opinions about the concept of brain death are irrelevant to whether Jahi McMath fulfills the accepted medical standards for brain death or whether she meets California's statutory definition of death

58. Dr. Schneider states in his declaration: "I understand that plaintiff's allegation that J. McMath is not dead is based on the opinion of D. Alan Shewmon, M.D. The dissenting theory proposed by Dr. Shewmon is that death is not a neurological phenomena [sic] and death only occurs after total cessation of the systemic circulation. This theory is contrary to the accepted medical and legal standards that brain death is a legal criterion for death. Dr. Shewmon's opinion is a philosophical minority opinion that denies and conflicts with the accepted medical standards in the Guidelines as well as California law." [Schneider declaration, p. 14, lines 12-17]

59. I feel obliged to respond before the court to this *ad hominem* remark. First, my opinion about the *conceptual rationale* for brain death is completely irrelevant to my competence as a pediatric neurologist and to my clinical judgment whether Jahi McMath fulfills or does not fulfill the accepted medical standards (the pediatric Guidelines) for brain death or whether she meets California's statutory definition of death. The "plaintiff's allegation that J. McMath is not dead" is not in any way whatsoever "based on" my opinion about the philosophical nature of death. That ought to be enough said, but the implication that I am some sort of lone outlier among my professional colleagues as regards this topic, and that my "minority opinion" should in essence be disregarded on account of conflict with "accepted medical standards... as well as California law," cannot be left unaddressed.

60. After completion of my training, for the next 11 years I accepted the mainstream understanding of brain death, that it was merely an alternative way of diagnosing the same physiological state as traditional death after cardiorespiratory arrest. I published and lectured to that effect, seconding the 1981 President's Commission's rationale that brain death was death by virtue of loss of integrative unity of the organism as a whole. [82] Then, in 1992 I consulted on a case that convinced me that at least some, perhaps many, cases of brain death were nevertheless human organisms as a whole, and therefore permanently comatose yet still living human beings. Subsequent research and clinical experience has only served to reinforce that conclusion.

61. Busy clinicians generally pay little attention to the philosophical, conceptual debates surrounding brain death, being content to follow the officially endorsed diagnostic algorithm and move on to the next patient. If one asks them whether they think brain death is death, the vast majority will say yes. In that superficial respect, my opinion that brain death is not true death is very much in the minority among clinical neurologists. But if one probes deeper and asks *why* they think brain death is death, one finds that about half of them actually think that brain-dead patients are biologically living human organisms–which is exactly my position–but that they are "dead" purely by virtue of irreversible loss of consciousness (contrary to my position and to every statutory definition of death). [83-85]

62. The editorial reinforcing my 1998 feature article in *Neurology* was written by one of the most prominent experts on and defenders of brain death at the time, the late Dr. Ronald Cranford. [3] Under the catchy title "Even the dead are not terminally ill anymore," he stated: "Alan Shewmon, MD, in this issue of *Neurology*, has accumulated convincing data that, among other things, undermine this somatic disintegration hypothesis.... Shewmon's article and the extensive case documentation, along with thoughtful concerns raised by scholars in recent years, create serious questions about the validity of the somatic disintegration basis for brain death as death and justify continued exploration of the issue." This is the same Dr. Cranford who wrote on another occasion: "It seems then that permanently unconscious patients have characteristics of both the living and the dead. It would be tempting to call them dead and then retrospectively apply the principles of death, *as society has done with brain death*." (emphasis added) [86, p. 243]

63. My presentation to the President's Council on Bioethics was instrumental in the Council's abandoning the integrative unity rationale for brain death, held by the 1981 President's Commission and mainstream neuroethics thereafter. [59] The Council's white paper cited my publications more frequently than those of any other author and seconded my critique of the mainstream rationale: "If being alive as a biological organism requires being a whole that is more than the mere sum of its parts, then it would be difficult to deny that the body of a patient with total brain failure can still be alive, at least in some cases." [9, p. 57] Two of the three personal

statements at the end of the white paper took my position, including that of Council Chairman Dr. Edmund Pellegrino. [87, 88]

64. Dr. Allan Ropper, Professor of Neurology at Harvard Medical School and Executive Vice Chair of Neurology at Brigham and Women's Hospital evidently implicitly accepts that, from a biological perspective, at least some brain-dead patients are comatose, living human organisms: "In exceptional cases [of brain death], however, the provision of adequate fluid, vasopressor, and respiratory support allows preservation of the *somatic organism in a comatose state* for longer periods." [89, p. 962] (emphasis added) The term "comatose state" applies only to living organisms that are normally conscious, not to corpses.

65. The late Dr. Fred Plum, one of the great luminaries of neurology regarding coma and brain death, during the question-and-answer session after my keynote address at the 3rd International Symposium on Coma and Death, Havana, Feb. 22-25, 2000, interjected: "OK, I'll grant you that the brain-dead body is a living human organism, but is it a human *person*?" – thereby shifting the death debate from biology to philosophy. At which he proceeded to propound person/mind/brain reductionism as the *real* reason why brain death is death, insisting that the biological vital status of the body is philosophically and ethically irrelevant – another example of conflict with California law and every other state law, by a neurologist with much more prestige than myself, Dr. Nakagawa or Dr. Schneider, and an ardent proponent of brain death.

66. Dr. James Bernat is Professor of Neurology at Dartmouth Medical School, a highly respected expert in neuroethics, and undoubtedly the most important defender of the mainstream rationale for brain death. Although he and I hold differing views about brain death, we regard each other's work with great esteem and mutual respect. In the chapter on brain death in the most recent edition of his book "Ethical Issues in Neurology," after discussing critiques of brain death theory by myself and others, he wrote with remarkable open-mindedness and humility: "I concede that the doctrine of whole brain death remains imperfect and that my attempts and those of others to respond to its shortcomings noted by critics remain inadequate." [59, p. 266] So as not to take this quotation out of context, I should add that it is hard to abandon a

life-long conceptual momentum, so he continued, almost ignoring what he had just written, "Yet, its conceptual soundness, intuitive appeal, universal acceptance by medical societies and lawmakers, and widespread societal acceptance mean that it is coherent biologically and has succeeded as public policy."

67. Freudian slips of various expert defenders of brain death also reveal that, at a deep level, they actually agree with me that brain-dead patients are biologically alive. To quote a few of the most striking examples:

68. In an article on a pregnant brain-dead woman supported for 107 days until delivery of the fetus, the mother was said to have died upon discontinuing support post-delivery, not when she became brain dead. [90] In the discussion section, regarding a related case the authors stated, "The [brain dead] mother died of spontaneous cardiac arrest 2 days after the delivery."

69. The neurosurgeon Albrecht Harders wrote: "Transcranial Doppler findings were obtained in 15 patients who fulfilled the clinical criteria for brain death... All of the patients died within 24 hours or upon discontinuation of the mechanical ventilation." [91, p. 115]

70. Dr. Fred Plum, mentioned above, wrote a book chapter on brain death, including a table entitled "Prolonged Visceral Survival after Brain Death," the fifth column of which had the heading "Mode of Death." [92, p. 38] Included in this column were entries of either "spontaneous cardiac arrest" or "respirator discontinued," implying that these patients were dead *not* by virtue of brain death, which had taken place from 26 to 201 days before, but rather by virtue of circulatory-respiratory arrest. Later in the same chapter, regarding a series of 73 brain-dead patients, Plum wrote: "half experienced asystole by the third day but the bodies of 2 *lived on* until the 10th and 16th day." (emphasis added) [92, p. 53]

71. Attachment 1 contains a bibliography of critiques of the biological "integrative unity" rationale for brain death, to demonstrate that a great many experts share my "minority opinion" regarding the traditional basis for equating brain death with death. (Of course the listing does not imply that I agree with all of the authors in every other way, especially with those who advocate "higher brain" (consciousness-based) formulations of death or the thesis that biological death does not ethically matter for harvesting of vital organs).

I declare under penalty of perjury under the laws of the State of California that the foregoing is true and correct. Executed this 9th day of June, 2017 at Encino, California.

D. Alan Shewmon

D. Alan Shewmon, M.D.

EXHIBIT 1

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