

SCHINDLER: My sister Terri Schiavo was alive like Jahi McMath

Ethics of brain death declaration

By Bobby Schindler - - *Thursday, January 16, 2014*

ANALYSIS/OPINION:

Much has been written about Jahi McMath in recent days. The 13-year-old Oakland, Calif., girl underwent surgery Dec. 9 to remove her tonsils. She was declared “brain-dead” after going into cardiac arrest.

Since that time, experts have opined on the ethics of the brain-death declaration, the family’s decision to transfer her to another facility, and the involvement of the Terri Schiavo Life & Hope Network in helping the family.

First, let me make it clear that our organization does not initiate contact with victims and their families or with the media. We did not contact the McMaths. We did not contact any media outlet.

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We were contacted, and we responded. We respond because that is our mission — to provide aid, comfort and support for vulnerable persons, and to speak truth to power. No one faces more risk in today's health care system than our medically vulnerable.

Since my family established the Terri Schiavo Life & Hope Network in response to my sister's death in 2005, we have been involved in hundreds of situations with families who find themselves in life-or-death situations.



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In every case, we put our resources at the service of the family. We share medical, legal and other needed resources. We provide emotional solidarity in their darkest moments and, always, prayers of support.

Second, we are not medical professionals. We do not know if Jahi will improve. We have no way of knowing that. We know the tests medical professionals conduct in these catastrophic cases are scientific in nature and quite exacting. We also know this: Human beings are imperfect. We can and do make mistakes; this includes medical professionals. There have been extraordinary instances of this that are breathtaking to behold. Take Zack Dunlap, for example. He experienced a catastrophic brain injury and was declared brain-dead. The family was not convinced. Two months later, Zack Dunlap walked out of that hospital. There are other examples.

Is Jahi McMath capable of being neurologically rehabilitated? Regardless, we think there is an even more basic question that must be answered first: Who has primacy in a life-and-death matter like this — the hospital or her parents?

Jahi's life has been entrusted to her parents. They are her legal guardians. If they believe she is alive, they ought to have the right to have her transferred to another acute-care facility — if they can find one that will take her.

They petitioned the courts for more time to assert their rights with the hospital. In the end, they prevailed, and the hospital agreed, and her

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possibly, care — if the originating hospital is unwilling to absorb additional expenses to sustain a life they think has ended.

This development will become increasingly significant in the days to come.

Finally, as a society, we are headed into uncharted territory. Demography and technology will increasingly force difficult and unwanted decisions on caregivers and loved ones.

The difficulty in making a pinpoint diagnosis in complex neurological matters, the soaring expense of life-sustaining medical technology, and the lucrative financial incentives to harvest the organs of a deceased Mr. Dunlap or Miss McMath will ultimately propel this issue into the forefront of public consciousness and discourse.

Perhaps not surprisingly, the current “procurement” market for human tissues and organs in the United States is quite large and driven by insufficient supply and heavy demand. The Milliman Report publishes the “going rate” for each of 12 different tissues and organs in the human body. A heart, for instance, goes for close to \$80,000; a kidney, \$65,000; a lung, \$70,000.

If all 12 tissues and organs could be harvested from a single patient declared brain-dead, however unlikely, their total value would exceed a half-million dollars.

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To what degree any given hospital might be influenced by any and all of this, no one can say with certainty. What can be said with certainty is this: Obamacare will exert increasing pressure on health care institutions to justify the amount and quality of care for the most vulnerable patients.

Another factor: There is mass confusion about what constitutes extraordinary medical treatment and what is ordinary and obligatory medical treatment. In all 50 states, basic nutrition and hydration is now considered extraordinary medical treatment. My sister, Terri, did not die because her ventilator was removed. She died of dehydration and starvation close to 14 torturous days and nights after her feeding tube supplying her food and water was removed by court order.

Had my parents had the option the McMaths were given, Terri would be alive today and, under the right physiatrist and protocols, they could have improved her lifestyle, commonly mislabeled quality of life.

How much Terri could have improved, I cannot say. We will simply never know. But what we do know is a growing number of patients who have God-given value and dignity will find themselves in horrific circumstances in the coming years. Their loved ones will suffer in a way few of us could ever know.

Recently, I received phone calls from three different families. Each family said they were in the same position as the McMaths. Hospitals were telling

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Bobby Schindler is the executive director of the Terri Schiavo Life & Hope Network. He is the brother of Terri Schiavo.

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v_4_gop · 16 Jan, 2014



... why was topic of organ donation part of the discussion?!?! ... so misleading !!!

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allele27 · 17 Jan, 2014 → v_4_gop



Because Schindler and company are using it to manipulate the credulous via fear.

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Christina · 17 Jan, 2014



I'm so sad to see that this hit piece is still up. It's a hit piece on modern medicine. It's a hit piece on those who are altruistic enough to become an organ donor, and those who are the beneficiaries of their grace. It's a hit piece on every established norm in our medical system, and it's meant to further inflame those who are naive enough to think that we live in some third world country where people are bartering with kidneys and lungs on street corners.

Finally, it's insulting to all of us who began this journey with Jahi and her family back in December--those of us who felt sorrow once her story broke, those of us who mourned with her family and grieved for the loss of a beautiful girl with a bright future. As the story has progressed, however, Jahi's family has lost most of their support from those of us who were aligned with them initially, and hit pieces like this only highlight the differences between those of us who can see the forest for the trees, and those who can't.

I've long said that you can make excuses or make progress. The time for excuses is long past. It's time to bury Jahi.



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and financial contributions for the care and preparation needed regarding this death....then the public will be satisfied and let this drop. Until this family makes a statement, then the family is going to be questioned.

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Kate Johnson · 17 Jan, 2014 → Christina 

Please keep in mind here....it was the family who called in the media to begin with.

I don't think any of us were unsympathetic at first.

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