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## News

## Jahi McMath's family to get award from Terri Schiavo foundation

By **MATTHIAS GAFNI** | mgafni@bayareanewsgroup.com | Bay Area News Group February 27, 2014 at 5:03 a.m.

The family of Jahi McMath will receive an award next month from the Terri Schiavo Life & Hope Network at the organization's award gala, the nonprofit announced Thursday.

The Oakland family will receive the Terri Schiavo Life & Hope Award, which honors an individual or family that "fights to protect the dignity of a loved one against overwhelming odds," according to a news release by Bobby Schindler, Schiavo's brother.

"The award to the McMath family recognizes the unconditional love they have for Jahi, and their courage as they continue the fight for their daughter against overwhelming odds," Schindler, the executive director of the Terri Schiavo Life & Hope Network, said in an email to this newspaper. He said Jahi's mother, father, uncle and grandmother plan to attend the March 27 awards gala.

"I am grateful for the award, I just wish it was under different terms," Omari Sealey, Jahi's uncle, said in a text message. "At the end of the day, my niece is still battling a horrific injury and it still hurts every day." On Dec. 9, 13-year-old Jahi went into Children's Hospital Oakland to undergo tonsil surgery and two other procedures to treat her severe sleep apnea. After significant post-surgical bleeding, she went into cardiac arrest and doctors declared her brain-dead. Her family fought through the courts to keep her on a ventilator, eventually securing her release from the hospital and sparking an international debate over end-of-life issues.

The family has recently said Jahi is "OK" at an undisclosed location, although critics argue that the girl died, as numerous doctors declared her brain activity had stopped, which equates to death in California. The Schiavo organization helped the family as they searched nationwide for a facility willing to accept a patient declared brain-dead.

"We are seeing a growing trend where physicians and hospital ethics committees are making medical decisions instead of family members," Schindler said in an email. "This was apparent in the case of Jahi McMath. Jahi's parents wanted to provide help for her after she experienced a profound brain injury while under hospital care, but their wish was denied. At the request of the family's attorney, Terri's Life & Hope Network intervened. We assembled a team of advocates that located a facility to provide the care Jahi needed, which gave her parents the opportunity to help their daughter."

The Pennsylvania-based nonprofit works to "protect the lives of the medically vulnerable from the threat of imposed death," according to its website.

In 2005, Schiavo's estranged husband won a court order to remove her from life support despite her family's opposition. She had been living for years in a permanent vegetative state, which is different from brain death. Her legal case, similar to Jahi's, brought contentious debate across the country on end-of-life decisions.

Jahi's family and their attorney did not immediately return requests for comment.

Radio personality and conservative talk show host Glenn Beck will speak at the March 27 awards gala in Philadelphia. Last year, former Alaska governor and vice presidential candidate Sarah Palin was the keynote speaker at the inaugural awards ceremony.

At that ceremony, the organization honored the parents of 20-month-old Joseph Maraachli, who suffered from a rare neurological disease that left him in a vegetative state. Similar to the Jahi case, a Canadian hospital refused to perform a tracheotomy on the infant and recommended he be removed from life support. His parents appealed in Canadian courts but were denied.

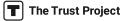
Eventually, a religious group removed the boy from the hospital and sent him to Cardinal Glennon Children's Hospital in St. Louis, where doctors performed the tracheotomy, which allowed the boy to return home.

He died several months later at home.

"Terri's life and legacy serve as a cautionary reminder of the immediate threat placed upon hundreds of thousands of persons with cognitive disabilities," Schindler said in a release. "We encourage all people to reflect on the ethical considerations of caring for those unable to do so for themselves, and believe that families, not hospital boards or politics, should dictate outcomes. We have seen a rise in the need for our advocacy efforts, especially in light of the health care crisis in our country."

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