A REPORT TO GOVERNOR JEB BUSH AND THE 6TH JUDICIAL CIRCUIT IN THE MATTER OF THERESA MARIE SCHIAVO

Pursuant to the requirements of H.B. 35-E (Chapter 2003-418, Laws of Florida) and the Order of the Hon. David Demers, Chief Judge, Florida 6th Judicial Circuit regarding the appointment and duties of a Guardian Ad Litem in the matter of Theresa Marie Schiavo, Incapacitated.

Respectfully Submitted
Jay Wolfson, DrPH, JD, Guardian Ad Litem for Theresa Marie Schiavo
1 December 2003

Introduction

Sometimes good law is not enough, good medicine is not enough, and all too often, good intentions do not suffice. Sometimes, the answer is in the process, not the presumed outcome. We must be left with hope that the right thing will be done well.

We are, each of us, standing in Theresa Marie Schiavo's shoes. Each of us is profoundly affected by the decisions that have and will be made in this case. Advocates of privacy rights and death with dignity, and advocates of right to life and rights of the disabled provide the compelling definitional parameters of this matter.

On 31 October 2003, pursuant to the requirements of Florida H.B. 35-E (Chapter 2003-418, Laws of Florida) and the order of the Hon. David Demers, Chief Judge, Florida 6th Judicial Circuit, a Guardian Ad Litem was appointed for a period of thirty days with the following charge:

> "…make a report and recommendations to the Governor as to whether the Governor should lift the stay that he previously entered. The report will specifically address the feasibility and value of swallow tests for this ward and the feasibility and value of swallow therapy. Additionally, the report will include a thorough summary of everything that has taken place in the trial court and the appellate court concerning this case."

The legislature instructed the court to appoint a Guardian Ad Litem to report to the court and the Governor. Florida law regarding the duties and powers of the Guardian Ad Litem

afford considerable scope and flexibility. The specific court ordered charge is narrowly constructed, particularly with respect to the questions to be addressed.

The recommendations proffered herein are intended for both the Governor and the court, on behalf of Theresa Marie Schiavo.

The Guardian Ad Litem's efforts have been to deduce and represent the best wishes and best interests of Theresa Schiavo. In that no express, written advance directive existed, determining what Theresa's wishes might be require a combination of substituted judgment, reasonable person considerations, and an aggressive, objective assessment of the massive legal and clinical record that has been compiled over thirteen years.

The entire court file of thirteen years, including items of evidence, has been reviewed and studied, with particular attention given to decision points in the case history that are reflected in motions to and orders by the Court. The case review has included clinical and medical records, discussions with members of the family, caregivers, and with medical, legal, bioethical and religious practitioners and scholars and the conduct of independent research into the substantive issues in this case. The GAL has met regularly with Ms. Schiavo, his ward.

Below, the questions posed to the GAL are addressed with recommendations, followed by an introduction to the case, a summary of the case, a summary of legal and medical issues in this case, and an expanded analysis of the recommendations at the conclusion of the report.

Questions and Recommendations

The two questions which the GAL is directed to address, and respective recommendations are:

1. Should the Governor lift the stay that he previously entered relative to Theresa Schiavo's feeding tube?

a. Yes. The Governor should lift the stay, if valid, independent scientific medical evidence clearly indicates that Theresa has no reasonable medical hope of regaining any swallowing function and/or if there is no evidence of cognitive function and no hope of improvement.
b. No. The Governor should not lift the stay if valid, independent scientific medical evidence clearly indicates that Theresa has a reasonable medical hope of regaining any swallowing function and/or if there is evidence of cognitive function with or without hope of improvement.

2. Is there feasibility and value in swallowing tests and swallowing therapy given the totality of circumstances?
    a. Yes. There is feasibility and value in swallowing tests and swallowing therapy being administered if the parties agree in advance as to how the results of these tests will be used with respect to the decision about Theresa's future. If the parties do not agree in advance as to how the tests will be used, then the court must be prepared to once again make a final judgment on the matter. Given the history of the case, this would not, in and of itself, assure a resolution, and is not, therefore, deemed either feasible or of value to Theresa Schiavo without prior agreement.

A detailed discussion of these recommendations within the context of the GAL's findings and analyses concludes this report.

Within the construct of the GAL's role, an additional recommendation is proffered to the court and to the Governor. During the more than nine years of adversarial relationships involving Theresa, no permanent Guardian Ad Litem has been appointed to stand exclusively in her shoes. It is the additional recommendation of the GAL that as long as controversy and an adversarial legal relationship exist in Theresa's case, a Guardian Ad Litem should be appointed to represent her exclusive interests. This is in no way intended to detract from or impugn the role of Theresa's existing Guardian, Michael Schiavo.

A central, statutory and moral role of the GAL is to seek to stand in Theresa Schiavo's shoes and speak for her with respect to her circumstance. The intentions of Theresa are central and vital to this case, because by law, they serve as a basis upon which reasoned decisions may be made regarding the removal of artificial life support.

To frame the issue for the reader, the GAL posits four, alternative, hypotheses that reasonably reflect the scope of circumstances affecting Theresa. These are intentionally graphic and specific. Responses that Theresa might proffer to these circumstances are then suggested.

Hypothesis I

Theresa, though profoundly disabled, with massive loss of cognitive function, maintains some cognitive capacity that has not been fully recognized. She is aware of aspects of her environment, though she requires great effort and energy to respond in the smallest way. She is capable of some interactive capacity, and can be brought, through therapy, to receive oral nutrition and hydration and possibly to enjoy other interactive competencies.

If she could speak to us, assume that Theresa would ask to be maintained and cared for under these circumstances.

Hypothesis II

Same as above, except Theresa's cognitive functions cannot improve, she will not be able to take oral nutrition and hydration, and she will not display any interactive or cognitive functions beyond what she has over the past 13 years. She can be maintained and cared for through an indefinite period of time.

If she could speak to us, assume that Theresa would ask to be maintained and cared for under these circumstances, or in the alternative, assume that Theresa would ask not to be maintained under these circumstances.

Hypothesis III

Theresa's exclusive awareness for 13 years, to the extent she may be aware of anything, is the equivalent of fear and perpetual horror. She is unable to hear, see, speak or interact, and unable to die, but she is not "locked in".

If she could speak to us Theresa would ask to be released from this condition and allowed to die.

Hypothesis IV

Same as I and/or II above, except the litigation surrounding Theresa continues, resulting in years of more of the same process that has been experienced to date, including orders and actions to remove her feeding tube and orders and actions to replace her feeding tube, multiple additional times.

If Theresa could speak to us, she would claim to be the victim of cruel and unusual punishment, protected by the U.S. Constitution.

Justice O'Connor's concurring opinion in Cruzan helps to establish the foundations for Hypotheses III and IV:

> A seriously ill or dying patient whose wishes are not honored may feel a captive of the machinery required for life-sustaining measures or other medical interventions. Such forced treatment may burden that individual's liberty interests as much as any state coercion. Cruzan v. Director, MDH, 497, U.S. 261 (1990)

Feasible and valuable recommendations on Theresa's behalf cannot be made without framing her circumstance in clear and express terms.

Theresa has survived in a diagnosed persistent vegetative state for more than thirteen years since her tragic accident and through nearly ten years of litigation; one clamping and one removal of her gastric feeding tube with subsequent replacement ordered by Governor Bush pursuant to a statutory intervention; the exhaustion of monies in a trust fund derived from a medical malpractice economic damages award; and the extensive, extraordinary, exquisite, nearly acrobatic legal efforts of attorneys and circuit court and appellate judges. Yet the matter of Theresa Schiavo remains unresolved.

Following nearly a decade of hostile and expensive litigation between parties having an interest in Theresa Schiavo, the Florida Legislature and the Governor of Florida have intervened in the case. That intervention, by way of a H.B. 35-E, passed during a special session of the Legislature, authorized the Governor to stay a court ordered removal of a gastric feeding tube and required the appointment of a Guardian Ad Litem (hereinafter, "GAL") to proffer recommendations to the Governor.

The charge to this GAL is to review the entire Theresa Schiavo court file, summarize it, and report recommendations to the Governor regarding his stay on removing artificial

nutrition, and with particularity on the "feasibility and value" of swallowing tests and swallowing therapy for Theresa Schiavo. These tests go the heart of the issues that have driven the contentions in this case for nearly a decade.

Merriam-Webster defines feasible as reasonable do-ability:

> 1 : capable of being done or carried out <a feasible plan>
> 2 : capable of being used or dealt with successfully : SUITABLE
> 3 : REASONABLE, LIKELY

If therefore, something is not feasible, it is not capable of being done or likely to be done without success.

Value is defined as relative worth:

> 1 : a fair return or equivalent in goods, services, or money for something exchanged
> 2 : the monetary worth of something : marketable price
> 3 : relative worth, utility, or importance <a good value at the price> <the value of base stealing in baseball> <had nothing of value to say>
> 4 a : a numerical quantity that is assigned or is determined by calculation or measurement <let x take on positive values> <a value for the age of the earth> b : precise signification <value of a word> ….
> 7 : something (as a principle or quality) intrinsically valuable or desirable <sought material values instead of human values
> (Merriam-Webster, 2001)

The relativity of "value" is clear, particularly as it may apply to a principle or quality, rather than empirical measurement.

If the Guardian Ad Litem's recommendations are neither feasible nor valuable – to and on behalf of Theresa Schiavo, then they fail in their purpose. For them to be feasible and valuable, they must be capable of being done in a manner that affords relative and intrinsic worth <u>for Theresa</u>; not for her husband; not for her parents and siblings; not for the Governor or the Legislature.

The history and key legal/medical events that have occurred since Theresa's tragic accident informed the charge to the Guardian Ad Litem.

Historical Facts in Theresa Marie Schiavo's Case

Theresa Marie Schiavo was born in the Philadelphia, Pennsylvania area on 3 December 1963 to Robert and Mary Schindler. She has two, younger siblings, Robert Jr., and Susan. Through the age of 18, Theresa was, according to her parents, very overweight, until she chose to lose weight with the guidance of a physician. She dropped from 250 pounds to around 150 pounds, at which time she met Michael Schiavo. They dated for many months and married in November of 1984. The Schiavo and Schindler families were close and friendly.

Theresa and Michael moved to Florida in 1986 and were followed shortly thereafter by Theresa's parents and siblings. Theresa worked for the Prudential Life Insurance Company and Michael was a restaurant manager.

About three years later, without the apparent knowledge of her parents, Theresa and Michael sought assistance in becoming pregnant through an obstetrician who specialized in fertility services. For over a year, Theresa and Michael received fertility services and counseling in order to enhance their strongly held desire to have a child. By this time, Theresa's weight had dropped even further, to 110 pounds. She was very proud of her fabulous figure and her stunning appearance, wearing bikini bathing suits for the first time and taking great pride in her improved good looks. Testimony and photographs bare witness to these facts.

On the tragic early morning of 25 February 1990, Theresa collapsed in the hallway of her apartment, waking Michael, who called Theresa's family and 911. The lives of Theresa, Michael and the Schindlers were to change forever.

Theresa suffered a cardiac arrest. During the several minutes it took for paramedics to arrive, Theresa experienced loss of oxygen to the brain, or anoxia, for a period sufficiently long to cause permanent loss of brain function. Despite heroic efforts to

resuscitate, Theresa remained unconscious and slipped into a coma. She was intubated, ventilated and trached, meaning that she was given life saving medical technological interventions, without which she surely would have died that day.

The cause of the cardiac arrest was adduced to a dramatically reduced potassium level in Theresa's body. Sodium and potassium maintain a vital, chemical balance in the human body that helps define the electrolyte levels. The cause of the imbalance was not clearly identified, but may be linked, in theory, to her drinking 10-15 glasses of iced tea each day. While no formal proof emerged, the medical records note that the combination of aggressive weight loss, diet control and excessive hydration raised questions about Theresa suffering from Bulimia, an eating disorder, more common among women than men, in which purging through vomiting, laxatives and other methods of diet control becomes obsessive.

Theresa spent two and a half months as an inpatient at Humana Northside Hospital, eventually emerging from her coma state, but not recovering consciousness. On 12 May 1990, following extensive testing, therapy and observation, she was discharged to the College Park skilled care and rehabilitation facility. Forty-nine days later, she was transferred again to Bayfront Hospital for additional, aggressive rehabilitation efforts. In September of 1990, she was brought home, but following only three weeks, she was returned to the College Park facility because the "family was overwhelmed by Terry's care needs."

On 18 June 1990, Michael was formally appointed by the court to serve as Theresa's legal guardian, because she was adjudicated to be incompetent by law. Michael's appointment was undisputed by the parties.

The clinical records within the massive case file indicate that Theresa was not responsive to neurological and swallowing tests. She received regular and intense physical, occupational and speech therapies.

Theresa's husband, Michael Schiavo and her mother, Mary Schindler, were virtual partners in their care of and dedication to Theresa. There is no question but that complete trust, mutual caring, explicit love and a common goal of caring for and rehabilitating Theresa, were the shared intentions of Michael Shiavo and the Schindlers.

In late Autumn of 1990, following months of therapy and testing, formal diagnoses of persistent vegetative state with no evidence of improvement, Michael took Theresa to California, where she received an experimental thalamic stimulator implant in her brain. Michael remained in California caring for Theresa during a period of several months and returned to Florida with her in January of 1991. Theresa was transferred to the Mediplex Rehabilitation Center in Brandon, where she received 24 hour skilled care, physical, occupational, speech and recreational therapies.

Despite aggressive therapies, physician and other clinical assessments consistently revealed no functional abilities, only reflexive, rather than cognitive movements, random eye opening, no communication system and little change cognitively or functionally.

On 19 July 1991 Theresa was transferred to the Sable Palms skilled care facility. Periodic neurological exams, regular and aggressive physical, occupational and speech therapy continued through 1994.

Michael Schiavo, on Theresa's and his own behalf, initiated a medical malpractice lawsuit against the obstetrician who had been overseeing Theresa's fertility therapy. In 1993, the malpractice action concluded in Theresa and Michael's favor, resulting in a two element award: More than $750,000 in economic damages for Theresa, and a loss of consortium award (non economic damages) of $300,000 to Michael. The court established a trust fund for Theresa's financial award, with SouthTrust Bank as the Guardian and an independent trustee. This fund was meticulously managed and accounted for and Michael Schiavo had no control over its use. There is no evidence in the record of the trust administration documents of any mismanagement of Theresa's estate, and the records on this matter are excellently maintained.

After the malpractice case judgment, evidence of disaffection between the Schindlers and Michael Schiavo openly emerged for the first time. The Schindlers petitioned the court to remove Michael as Guardian. They made allegations that he was not caring for Theresa, and that his behavior was disruptive to Theresa's treatment and condition.

Proceedings concluded that there was no basis for the removal of Michael as Guardian Further, it was determined that he had been very aggressive and attentive in his care of Theresa. His demanding concern for her well being and meticulous care by the nursing home earned him the characterization by the administrator as "a nursing home administrator's nightmare". It is notable that through more than thirteen years after Theresa's collapse, she has never had a bedsore.

By 1994, Michael's attitude and perspective about Theresa's condition changed. During the previous four years, he had insistently held to the premise that Theresa could recover and the evidence is incontrovertible that he gave his heart and soul to her treatment and care. This was in the face of consistent medical reports indicating that there was little or no likelihood for her improvement.

In early 1994 Theresa contracted a urinary tract infection and Michael, in consultation with Theresa's treating physician, elected not to treat the infection and simultaneously imposed a "do not resuscitate" order should Theresa experience cardiac arrest. When the nursing facility initiated an intervention to challenge this decision, Michael cancelled the orders. Following the incident involving the infection, Theresa was transferred to another skilled nursing facility.

Michael's decision not to treat was based upon discussions and consultation with Theresa's doctor, and was predicated on his reasoned belief that there was no longer any hope for Theresa's recovery. It had taken Michael more than three years to accommodate this reality and he was beginning to accept the idea of allowing Theresa to die naturally rather than remain in the non-cognitive, vegetative state. It took Michael a long time to

consider the prospect of getting on with his life – something he was actively encouraged to do by the Schindlers, long before enmity tore them apart. He was even encouraged by the Schindlers to date, and introduced his in-law family to women he was dating. But this was just prior to the malpractice case ending.

As part of the first challenge to Michael's Guardianship, the court appointed John H. Pecarek as Guardian Ad Litem to determine if there had been any abuse by Michael Schiavo. His report, issued 1 March 1994, found no inappropriate actions and indicated that Michael had been very attentive to Theresa. After two more years of legal contention, the Schindlers action against Michael was dismissed with prejudice. Efforts to remove Michael as Guardian were attempted in subsequent years, without success.

Hostilities increased and the Schindlers and Michael Schiavo did not communicate directly. By June of 1996, the court had to order that copies of medical reports be shared with the Schindlers and that all health care providers be permitted to discuss Theresa's condition with the Schindlers – something Michael had temporarily precluded.

In 1997, six years after Theresa's tragic collapse, Michael elected to initiate an action to withdraw artificial life support from Theresa. More than a year later, in May of 1998, the first petition to discontinue life support was entered. The court appointed Richard Pearse, Esq., to serve as Guardian Ad Litem to review the request for withdrawal, a standard procedure.

Mr. Pearse's report, submitted to the court on 20 December 1998 contains what appear to be objective and challenging findings. His review of the clinical record confirmed that Theresa's condition was that of a diagnosed persistent vegetative state with no chance of improvement. Mr. Pearse's investigation concluded that the statements of Mrs. Schindler, Theresa's mother, indicated that Theresa displayed special responses, mostly to her, but that these were not observed or documented.

Mr. Pearse documents the evolving disaffections between the Schindlers and Michael Schiavo. He concludes that Michael Schiavo's testimony regarding the basis for his decision to withdraw life support – a conversation he had with his wife, Theresa, was not clear and convincing, and that potential conflicts of interest regarding the disposition of residual funds in Theresa's trust account following her death affected Michael and the Schindlers – but he placed greater emphasis on the impact it might have had on Michael's decision to discontinue artificial life support. At the time of Mr. Pearse's report, more than $700,000 remained in the guardianship estate.

Mr. Pearse concludes that Michael's hearsay testimony about Theresa's intent is "necessarily adversely affected by the obvious financial benefit to him of being the sole heir at law…" and "…by the chronology of this case…", specifically referencing Michael's change in position relative to maintaining Theresa following the malpractice award.

Mr. Pearse recommended that the petition for removal of the feeding tube be denied, or in the alternative, if the court found the evidence to be clear and convincing, the feeding tube should be withdrawn.

Mr. Pearse also recommended that a Guardian Ad Litem continue to serve in all subsequent proceedings.

In response to Mr. Pearse's report, Michael Schiavo filed a Suggestion of Bias against Mr. Pearse. This document notes that Mr. Pearse failed to mention in his report that Michael Schiavo had earlier, formally offered to divest himself entirely of his financial interest in the guardianship estate. The criticism continues to note that Mr. Pearse's concern about abuse of inheritance potential was directly solely at Michael, not at the Schindlers in the event they might become the heirs and also choose to terminate artificial life support. Further, significant chronological deficits and factual errors are noted, detracting from and prejudicing the objective credibility of Mr. Pearse's report.

The Suggestion of Bias challenges premises and findings of Mr. Pearse, establishing a well pleaded case for bias.

In February of 1999, Mr. Pearse tendered his petition for additional authority or discharge. He was discharged in June of 1999 and no new Guardian Ad Litem was named.

Actions by the Schindlers to remove Michael as Guardian and to block the petition to remove artificial life support took on a frenetic quality at this juncture. More external parties on both sides made appearances as potential interveners.

On 11 February 2000, consequent to hearings and the presentation of competent evidence, Judge Greer ordered the removal of Theresa's artificial life support.

The Schindlers aggressively sought means by which to stop the removal of Theresa's feeding tube. Most of the motions in these efforts were denied, but not without apparent careful and detailed review by the court, often involving hearings at which considerable latitude was afforded the Schindlers in their efforts to proffer testimony and admit evidence.

The motion and hearing process continued through 2000. Then the Schindler's sought to introduce new evidence that was believed to be of a sufficiently substantial nature as to change the court's decision regarding the removal of the feeding tube.

The hearings and testimony before the trial court leading to the decision to discontinue artificial life support included admitted hearsay from Theresa's brother-in-law (Michael Schiavo's brother) and his wife (Michael's Schiavo's sister-in-law) along with testimony from Michael.

The testimony of these parties referenced specific conversations in which Theresa commented about her desire never to be placed on artificial life support. The testimony

reflected conversations at or proximate to funerals of close family members who had been on artificial life support. The context and content of the testimony, while hearsay, was deemed credible and consistent and was used by the court as a supporting bases for its decision to discontinue artificial life support.

The Schindler's new evidence ostensibly reflected adversely on Michael Schiavo's role as Guardian. It related to his personal romantic life, the fact that he had relationships with other women, that he had allegedly failed to provide appropriate care and treatment for Theresa, that he was wasting the assets within the guardianship account, and that he was no longer competent to represent Theresa's best interests.

Testimony provided by members of the Schindler family included very personal statements about their desire and intention to ensure that Theresa remain alive. Throughout the course of the litigation, deposition and trial testimony by members of the Schindler family voiced the disturbing belief that they would keep Theresa alive at any and all costs. Nearly gruesome examples were given, eliciting agreement by family members that in the event Theresa should contract diabetes and subsequent gangrene in each of her limbs, they would agree to amputate each limb, and would then, were she to be diagnosed with heart disease, perform open heart surgery. There was additional, difficult testimony that appeared to establish that despite the sad and undesirable condition of Theresa, the parents still derived joy from having her alive, even if Theresa might not be at all aware of her environment given the persistent vegetative state. Within the testimony, as part of the hypotheticals presented, Schindler family members stated that even if Theresa had told them of her intention to have artificial nutrition withdrawn, they would not do it. Throughout this painful and difficult trial, the family acknowledged that Theresa was in a diagnosed persistent vegetative state.

The court denied the Schindler's motions to remove the guardian, allowing that the evidence was not sufficient and in some instances, not relevant. It set a date for the artificial life support to be discontinued, as of 24 April 2001.

The decision was appealed to the Florida 2nd District Court of Appeals (DCA), and was affirmed in January 2001. The requested appeal to the Florida Supreme Court was denied on 23 April 2001, one day before the scheduled removal of Theresa's feeding tube.

On 24 April 2001, Theresa Schiavo's artificial feeding tube was clamped, and she ceased receiving nutrition and hydration. Under normal circumstances, Theresa would die naturally within a week to ten days.

Two days after the clamping of Theresa's feeding tube, the Schindlers filed a civil action in their capacity as "natural guardians" for Theresa. The trial court, in emergency review, granted a temporary injunction and the tube was unclamped. Michael Schiavo filed an emergency motion to vacate the injunction. This led to the second review and appeal to the 2nd DCA.

The 2nd DCA found that the intention of Florida Statutes 765 with respect to matters such as Theresa's, is to help expedite proceedings of the court when decisions have been made by the bona fide guardian. The 2nd DCA also noted that the Court had acted independently as proxy decision maker regarding the removal of artificial life support.

In October 2001, the 2nd DCA concluded that the Schindlers "have presented no credible evidence suggesting new treatment can restore Mrs. Schiavo." The injunction was lifted and plans moved forward to discontinue artificial nutrition.

Fresh and exhaustive motions regarding new evidence were again crafted and proffered to the trial court by the Schindlers resulting in a lengthy hearing. Affidavits from medical doctors and others alleged that Theresa's condition could be improved.

In particular, the sworn statement of a single, osteopathic physician, Dr. Webber, claimed that he could improve Theresa's condition and had done so in like and similar cases.

The quality of evidence in this affidavit was marginal, but the court allowed it to create a colorable entitlement to additional medical review. The case was remanded to the trial court with the charge that each side would select two expert physicians (a neurologist or a neurosurgeon, according to the court) and agree between them regarding a fifth, and if they could not agree on the fifth, the court would select it.

By May of 2002, the physicians were selected by both sides, but no agreement could be reached about a fifth, so the court selected one. Curiously and surprisingly, Dr. Webber, who had served as the basis for this entire process at the 2nd DCA, did not participate in the exams or the procedure.

Each of the physicians was afforded access to Theresa for the purpose of conducting a thorough examination. Video tape recordings were made of some of the examinations along with segments in which family members interacted with Theresa. The physicians were deposed and proffered testimony regarding their findings.

Written reports of the examinations were prepared by all five physicians, and a very detailed hearing was held in October of 2002.

The clinical evidence presented by the five physicians reflected their examinations and reviews of the medical records. Four of the physicians were board certified in neurology, as suggested by the court, and one physician was board certified in radiology and hyperbaric medicine. All of the physicians had excellent pedigrees of medical training.

The scientific quality, value and relevance of the testimony varied. The two neurologists testifying for Michael Schiavo provided strong, academically based, and scientifically supported evidence that was reasonably deemed clear and convincing by the court. Of the two physicians testifying for the Schindlers, only one was a neurologist, the other was a radiologist/hyperbaric physician. The testimony of the Schindler's physicians was substantially anecdotal, and was reasonably deemed to be not clear and convincing.

The fifth physician, chosen by the court because the two parties could not agree, presented scientifically grounded, academically based evidence that was reasonably deemed to be clear and convincing by the court.

Following exhaustive testimony and the viewing of video tapes, the trial court concluded that no substantial evidence had been presented to indicate any promising treatment that might improve Theresa's cognition. The court sought to glean scientific, case, research-based foundations for the contentions of the Schindler's physician experts, but received principally anecdotal information.

Evidence presented by Michael Schiavo's two physicians and the fifth physician selected by the court was reasonably deemed clear and convincing in support of Theresa being in a persistent vegetative state with no hope for improvement.

Simultaneous appeals of this decision and renewed actions to remove Michael Schiavo as Guardian were initiated based upon new evidence.

The June 2003 appeal to the 2nd DCA was Schiavo IV. The 2nd DCA panel of judges engaged in what approximated a de novo review of all of the facts, testimony and video tapes presented at trial. The appellate court affirmed the trial court's ruling and its conclusions, and in addition, ordered the trial court to set a hearing date for removal of the artificial life support.

The trial court set 15 October 2003 as the date for the removal of Theresa's artificial nutrition tube.

The Schindler's renewed efforts to remove Michael Schiavo as Guardian, and to disqualify judges, were not successful. Multiple amicus briefs and affidavits from parties supporting the Schindler's were submitted through the Schindler's actions and in some instances, independently to the court.

By mid 2003, the landscape and texture of Theresa Schiavo's case underwent profound changes. National media coverage, active involvement by groups advocating right to life, and the attention of the Governor's office and the Florida Legislature, catapulted Theresa's case into a different dimension.

The Schindlers, acting on behalf of Theresa, filed a motion in federal district court seeking a preliminary injunction to stay the removal of the artificial life support from Theresa, scheduled to occur on 15 October 2003. On 6 October 2003, Florida Governor Jeb Bush filed an Amicus brief in support of the motion for a preliminary injunction. The brief argues that removal of artificial nutrition, resulting in death, should be avoided if that person can take oral nutrition and hydration. The Governor predicates his memorandum on the pivotal question as to whether Theresa could ingest food and water on her own. That Theresa is in a diagnosed, persistent vegetative state is explicitly recognized.

On 15 October 2003, Theresa Maria Schiavo's artificial feeding tube was disconnected, for the second time.

The Florida legislature, in special session, passed HB 35 E on 21 October 2003, authorizing the Governor to stay the disconnection of the artificial feeding tube and required, among other things, the appointment of a Guardian Ad Litem to produce this report.

On that same day, 21 October 2003, the artificial feeding tube was re-inserted per the stay ordered by Governor Bush. Other suits and actions were initiated immediately. The governor became a named party in the matters involving Theresa Schiavo.

This Guardian Ad Litem is not addressing any of the Constitutional causes of action arising subsequent to the passage of HB 35 E and the Governor's action.

In addition to the historical facts in the case, a summary of the nature of Florida's legal and policy treatment of decisions involving death and dying, artificial life support, and artificial nutrition, are essential to the charge of the Guardian Ad Litem.

Guardian Ad Litem's Findings

The Information Acquisition Process

Upon appointment, this Guardian Ad Litem met with the Schindler family and their attorneys, Michael Schiavo and his attorney, and with the Ward, Theresa Marie Schiavo. The establishment of a trusting relationship with all of the parties was a priority in order to ensure that any recommendations would be feasible and valuable. Only thirty days were afforded to the process.

All court records were accessed and reviewed, including all items of evidence in the case. Extensive discussions were held with family members and caregivers along with the acquisition and review of background data and information from the case file to assist the Guardian Ad Litem in becoming as personally acquainted with his ward, Theresa Schiavo as possible, in the short time available. The Guardian Ad Litem has made numerous and frequent visits to Theresa at the hospice where she resides, including an arranged visit with her parents to observe interactions. The Guardian ad Litem has met with and discussed aspects of Theresa's case with hospice staff, physician cardiologists, gastroenterologists, internists, neurologists, neurosurgeons, trauma specialists, anesthesiologists, swallowing disorder specialists; speech pathologists specializing in rehabilitation, swallowing tests and swallowing therapy; and with clergy, elder law specialists, bioethicists, and health policy specialists. In addition to reading the nearly 30,000 pages of court records, the Guardian Ad Litem has conducted a review of the medical literature and has received thousands of unsolicited documents, sources of referral, claims regarding successful interventions, and wishes of good luck. Governor Bush, to whom this report is directed, requested a meeting with the Guardian Ad Litem to discuss the charge. The Guardian Ad Litem met with the Governor, his General Counsel and private external counsel to review the Guardian Ad Litem's plan and direction. The

meeting was valuable in establishing the expanded trust among the parties that the Guardian Ad Litem has sought to cultivate from the inception if his appointment.

The Evolution of the Law about Dying and Nutrition in Florida

Our society is at a legal, political, biotechnological, bioethical and spiritual crossroad. Theresa Schiavo is alternately depicted as a living, loving person, capable of interacting at a level of cognition with her family and deserving of the right to continue to live --- and as a tragically and profoundly brain damaged person, who earlier expressed a desire never to find herself in a circumstance analogous to waking up in a coffin – and being there forever. But she cannot speak to us now. So we must rely upon the auspices of good law and good medicine and the good intentions of those who marshal these arts in order to do our best to do the right thing well for Theresa Schiavo.

During the early 1970s the States began to revise their Probate Codes. There were many reasons for this, including a rapidly aging population, larger numbers of aged persons in the population, people living longer, new and advancing medical technologies that enhanced, extended and affected life, and changing values and orientations about death, dying and the medical-decision processes. These matters have been seriously addressed through a combination of inquiries and actions by church leaders, legislators, medical scientists, and the courts, as all have sought to respond to emerging issues such as those in the Quinlan, Cruzan, Browning, and now the Schiavo cases.

States cooperated with the federal Administration on Aging to address legislative and policy challenges surfacing around these matters. A particularly important topic related to medical technology and its use in the care, treatment and maintenance of patients, is when, who and by what means "artificial" life support and other medical interventions should or could be removed or never withheld in the first place.

Today, most states would afford an adult person the right to deny most health care treatments. But if the patient is a minor, unconscious, in a coma, in a vegetative state, or unable to communicate personal wishes and intentions, there are serious moral, ethical

and legal questions that demanded attention. There had been inconsistencies, even within states, as to how decisions regarding termination or removal or withholding a procedure were made. There was also a long standing, well accepted recognition that the relationship between the patient and the physician – the sacred trust – served as the foundation for how and where and when many of these decisions would be made. Often, physicians, in consultation with family members and the patient have done what was deemed to be in best interests of the patient, given the physician's medical opinion and the express, known or believed intentions of the patient.

To reduce ambiguities, many states began to encourage and accept written advance directives as the basis for decisions regarding end of life treatment. Living wills, durable powers of attorney for health care and health care surrogate documents, stating a person's explicit intentions regarding end of life care, became increasingly accepted and even formalized into the statutory framework of most states. A written expression was deemed to be an important element in this process to avoid the possibility of confusion or uncertainty with respect to a person's intention regarding their health and medical care.

Throughout the 1980s and 1990s, Florida lawmakers struggled with how they would provide individuals with the prerogatives for establishing their wishes regarding end of life decisions, while at the same time, protecting against perceived and actual abuses and assisted suicides. Among the most sensitive of issues is this regard has been the withdrawal of artificial life support in the form of nutrition and hydration. The idea of withholding or withdrawing these has created significant debates within and across religious, philosophical and political groups and interests. But the topic has been addressed at great lengths by each of these groups, and there is surprising consensus in principle and even in practice.

The current, generally accepted applications to terminal illness or persistent vegetative state define artificial feeding as artificial life support that may be withheld or withdrawn. In 1989, the Florida Legislature permitted the withdrawal of artificial nutrition and hydration under very specific circumstances. In 1999, following extensive bipartisan

efforts, life-prolonging procedures were redefined as "any medical procedure, treatment, or intervention, including artificially provided sustenance and hydration, which sustains, restores, or supplants a spontaneous vital function." It is noteworthy that the general principle of artificial nutrition as artificial life support that may be removed in terminal and even vegetative state conditions is reflected in nearly all state's laws and within the guidelines of end of life care enunciated by the American Conference of Catholic Bishops and other religious denominations.

These general principles are in no way intended to encourage or condone suicide or assisted suicide. But they reflect the acceptance of artificial nutrition as artificial life support that may be withdrawn or withheld as a matter of public policy, when these decisions capture the intentions of the person and with the premise that people should not be required to remain "artificially alive", or to have their natural peaceful deaths postponed and prolonged if they would otherwise choose not to, and that they should be allowed to die with dignity, and return, if their beliefs so accommodate, to God.

When written advance directives are not available, and the affected person is incompetent and unable to communicate, a decision to discontinue nutrition and hydration is especially challenging. But Florida law, as reflected in F.S. 765, and as interpreted through In re Guardianship of Browning, 568 So. 2d 4 (Fla. 1990), provide for a substituted judgment basis for such decisions and/or the presentation of clear and convincing evidence to demonstrate the intentions of the person.

It has been suggested that in the case of incapacitated persons, particularly those who have not expressed an advance directive, the "clear and convincing" evidence standard for establishing the intent to discontinue artificial life support is insufficient and incongruous. The insufficiency, it is argued, is because of the possibility of using information that is not accurate, complete or even honest. The incongruity is related to the "beyond a reasonable doubt" standard that serves as the basis for decisions to convict and then execute capitol felons.

If persons unable to speak for themselves have decisions made on their behalf by guardians or family members, the potential for abuse, barring clear protections, could lead to a "slippery slope" of actions to terminate the lives of disabled and incompetent persons. And it is not difficult to imagine bad decisions being made in order to make life easier for a family or to avoid spending funds remaining in the estate on the maintenance of a person.

There is, of course, the other side of that slippery slope, which would be to keep people in a situation they would never dream of: unable to die, unable to communicate, dependent for everything, and unaware, being maintained principally or entirely through state resources – and for reasons that may relate to guilt, fear, needs or wants of family members, rather than what the person's best wishes might otherwise have been.

And there is the chillingly practical, other public policy matter of the cost of maintaining persons diagnosed in persistent vegetative states and terminal conditions alive for potentially indefinite periods of time – at what inevitably becomes public expense. Here the "reasonable person" standard, with respect to how one would want to be treated were they in Theresa's shoes affects the discussion. This is not easy stuff, and should not be.

In withholding or withdrawing life support, or in keeping a person alive, there is the risk of transposing intentions and values. The reasoned, even substituted judgment decisions of guardians or loved ones may be based upon either a "quality of life determination", or the desires of family members. This remains a risk in a system that does not require an explicit, advance directive.

Cruzan and the Role of States in Guidelines for Medical Decisions

A legal analysis of the tens of thousands of pages of documents in the case file, against the statutory legal guidelines and the supporting case law, leads the GAL to conclude that all of the appropriate and proper elements of the law have been followed and met. The law has done its job well. The courts have carefully and diligently adhered to the prescribed civil processes and evidentiary guidelines, and have painfully and diligently

applied the required tests in a reasonable, conscientious and professional manner. The disposition of the courts, four times reviewed at the appellate level, and once refused review by the Florida Supreme Court, has been that the trier of fact followed the law, did its job, adhered to the rules and rendered a decision that, while difficult and painful, was supported by the facts, the weight of the evidence and the law of Florida.

A prevailing legal sentiment is that matters such as those in Theresa's case are best addressed by states, their legislatures and their courts – rather than by the federal judiciary.

Justice Scalia has admonished us to rely upon and accept the role of state lawmakers and laws to address issues of this very nature. Though his point of reference was Missouri law relative to an evidentiary standard, his message remains that it is up to states to establish the rules and guidelines in these matters.

> I would have preferred that we announce, clearly and promptly, that the federal courts have no business in this field; that American law has always accorded the State the power to prevent, by force if necessary, suicide - including suicide by refusing to take appropriate measures necessary to preserve one's life; that the point at which life becomes "worthless," and the point at which the means necessary to preserve it become "extraordinary" or "inappropriate," are neither set forth in the Constitution nor known to the nine Justices of this Court any better than they are known to nine people picked at random from the Kansas City telephone directory; and hence, that even when it is demonstrated by clear and convincing evidence that a patient no longer wishes certain measures to be taken to preserve her life, *it is up to the citizens of Missouri to decide, through their elected representatives, whether that wish will be honored.* It is quite impossible (because the Constitution says nothing about the matter) that those citizens will decide upon a line less lawful than the one we would choose; and it is unlikely (because we know no more about "life-and-death" than they do) that they will decide upon a line less reasonable. (emphasis added) Cruzan v. Director, MDH, 497, U.S. 261 (1990)

And while he might not agree with a particular state's method for addressing a matter – he not only defers to the states – but further admonishes us to avoid the politicization of legislation in these matters:

> I am concerned, from the tenor of today's opinions, that we are poised to confuse that [497 U.S. 261, 293] enterprise as successfully as we have confused the enterprise of legislating concerning abortion - requiring it to be conducted against a background of federal constitutional imperatives that are unknown because they are being newly crafted from Term to Term. That would be a great misfortune. Cruzan v. Director, MDH, 497, U.S. 261 (1990)

In this context, it is vital to realize that Florida Statutes, Florida Rules of Evidence, Florida Rules of Civil Procedure and Florida case law were the basis for the past 13 years of litigation and conclusions of law in Theresa's case.

Florida carefully and intentionally crafted its laws about death and dying and decisions about how persons, situated similarly to Theresa, might be treated by the law. While Florida remains among a minority of states that has provisions for proxy and/or surrogate decision making in matters of removal of artificial feeding when there is no written living will – it is fair to say that this was a conscious, deliberate process within the Florida legislative arena. This process actively involved a broad cross section of political, philosophical and religious interests, public hearings, and the deliberate sharing of very specific language with vested parties, within and outside of government. Based upon Justice Scalia's admonition, one should exercise caution in re-crafting state laws from term to term.

Speaking with the majority in Cruzan, Justice Stevens further admonishes us to accept state legislation in matters of death and dying:

> "Choices about death touch the core of liberty. . . . [N]ot much may be said with confidence about death unless it is said from faith, and that alone is reason enough to protect the freedom to conform choices about death to individual conscience." Our salvation is the Equal Protection Clause, which requires the democratic majority *to accept for themselves and their loved ones what they impose on you and me.* This Court need not, and has no authority to, inject itself into every field of human activity [497 U.S. 261, 301] where irrationality and oppression may theoretically occur, and if it tries to do so, it will destroy itself. (emphasis added) Cruzan v. Director, MDH, 497, U.S. 261 (1990)

Justice O'Connor reinforces the High Court's view that it is to the states and their legislative process that the Supreme Court turns to grapple with these matters:

> Today we decide only that one State's practice does not violate the Constitution; the more challenging task of crafting appropriate procedures for safeguarding incompetents' liberty interests is entrusted to the "laboratory" of the States, New State Ice Co. v. Liebmann, 285 U.S. 262, 311 (1932) (Brandeis, J., dissenting), in the first instance. Cruzan v. Director, MDH, 497, U.S. 261 (1990)

And even if we are not happy with the result in a case – or the application and interpretation of the law, we are reminded by Chief Justice Renquist, writing for the Court that general rules of law – indeed, even the law itself, is neither flawless nor faultless:

> But the Constitution does not require general rules to work faultlessly; no general rule can. Cruzan v. Director, MDH, 497, U.S. 261 (1990)

In In re Guardianship of Browning, 568 So. 2d 4 (Fla. 1990) the Florida Supreme Court highlighted a privacy interest in the decision regarding the removal of a feeding tube in an elderly, sick woman. The reasoning and methods deployed in that case have served as one of the foundations for the Florida courts' actions and conclusions in Theresa's case, including the proxy power of the court to make decisions about discontinuation of artificial life support. And while Browning can be distinguished from Theresa's case, it was adopted by the trial court and the court of appeal reasonably and rationally.

But the law has failed to provide Theresa a conclusion and resolution.

The elements of the law include specific provisions for decision making regarding the removal of artificial life support when explicit, written, advance directives have not been executed by a person.

Not all states deploy the specific guidelines and measures adopted by Florida. Many states refuse to accept anything but advance, written directives of the person as a basis for removal of artificial life support. Florida has chosen to employ guidelines that include surrogate decisions by the bona fide legal guardian and/or clear and convincing evidence as to the intentions of the person.

In Theresa's case, evidence regarding her intentions consisted of admitted hearsay regarding conversations between Theresa and her spouse and spousal relatives. The context and nature of this hearsay were deemed sufficiently probative, competent and reliable to serve as a basis for admission, and was determined to be sufficiently clear and convincing. The court then served as proxy decision maker, essentially assuming the role of legal guardian. The privacy interests of the person, as established in the Florida Constitution, and as articulated with specificity in Browning (In re Guardianship of Browning, 568 So. 2d 4 (Fla. 1990)) served as the legitimate legal bases for the court's conclusions to withdraw life support consistent with Florida Statute, 765.

Evidence regarding the persistent vegetative state consisted of highly credible medical testimony and documentation reflecting both early and recently performed neurological examinations and a case history that included early swallowing studies conducted multiple times nearly ten years ago.

The Swallowing Test and Neurological Function

The review of the medical and clinical evidence in the case goes directly to the issues of the feasibility and value of swallowing tests and swallowing therapy, and to the relationship between neurological function and swallowing food and liquid.

Three, independent sets of swallowing tests were performed early in Theresa's medical treatment: 1991, 1992 and 1993. Each of these determined that Theresa was not able to swallow without risk of aspiration (and consequent infection).

Swallowing tests and swallowing therapy address many of the core issues in contention. If Theresa can swallow, then she can take nutrition and hydration orally, and it is argued that she would not elect to stop eating. But to orally eat and drink, Theresa must possess cognitive capacity beyond mere reflex, or she will not only fail to ingest, but could easily aspirate substances into her lungs and be subjected to infections and subsequent death.

If Theresa were capable of orally taking nutrition and hydration, this GAL suggests that Theresa's reasoned best wishes might be not to choose to stop eating, depending upon the difficulty, burden to others and costs involved. The conduct of swallowing tests by an independent, competent clinician, shielded from the public process, would provide competent, scientifically based medical evidence as to Theresa's ability to swallow and whether swallowing therapy could improve her capability to orally eat and hydrate.

Three general methods of swallowing test can be performed to assess swallowing capacity and swallowing potential. A bedside test examines cranial nerve function, speech potential and trials of certain food textures through spoons, syringes, straws and cups. It is relatively non-invasive and low risk, with the exception of silent aspiration – which is the unnoticed sucking of food or water into the lungs, rather than transporting it down the throat.

The second is also bedside based test, call Flexible Endo Exam Swallowing (FEES). A nasal tube is inserted and spontaneous swallowing is observed, again using various textures of liquid and foods. This is a bit more objective and also has the advantage of being done at the bedside.

The recognized gold standard test is the modified barium swallowing test, generally done in a hospital or at a facility that has radiology equipment. Theresa's three previous tests were barium swallowing tests.

Swallowing therapy, if swallowing potential is identified, may consist of posture management (head and neck positioning), training to focus on the food ingestion process, holding utensils and other activities. Electrical stimulation therapy has been promoted, but there is no objective, scientific evidence as to its effectiveness or value.

The ability to orally ingest food and water – to swallow substances other than saliva, is predicated on a level of cognitive capacity. Without cognitive capacity, the intentional act of oral nutrition and hydration is likely to lead to aspiration. Eating and drinking are

not unconscious processes. Therefore, Theresa's neurological status is directly linked to her ability to swallow.

Early in Theresa's care, neurological examinations were performed to assess her cognitive capacity. Competent medical practitioners determined that Theresa was in what has been consistently defined as a persistent vegetative state – a finding that throughout the litigation was not disputed by either side. Quite recently, the Schindlers have disputed that Theresa is in a persistent vegetative state, and in the alternative, they have argued that even if she is, she deserves to live and be maintained via artificial nutrition and hydration.

Like the law, which offers prescriptive guidelines to be applied on a case by case basis, Neurology, a nationally recognized specialty within Medicine, has sought to define the elements of disease states for purposes of treatment. The persistent vegetative state has been accepted as a formal diagnosis in modern American medical practice and it is recognized by American Academy of Neurology as:

> The vegetative state is a clinical condition of complete unawareness of the self and the environment, accompanied by sleep-wake cycles, with either complete or partial preservation of hypothalmic and brain stem autonomic functions. In addition, patients in a vegetative state show no evidence of sustained, reproducible, purposeful, or voluntary behavioral responses to visual, auditory, tactile, or noxious stimuli; show no evidence of language comprehension or expression; have bowel and bladder incontinence; and have variably preserved cranial-nerve and spinal reflexes. We define persistent vegetative state as a vegetative state present one month after acute traumatic or nontraumatic brain injury, or lasting in least one month in patients with degenerative or metabolic disorders or developmental malformations.
>
> The Multi-Society Task for on PVS, *Medical Aspects of the Persistent Vegetative State,* New England Journal of Medicine, 330:1499-1508, May 26, 1994.

A particularly disarming aspect of persons diagnosed with persistent vegetative state is that they have waking and sleeping cycles. When awake, their eyes are often open, they make noises, they appear to track movement, they respond to deep pain, and appear startled by loud noises. Further, because the autonomic nervous system those brain

related functions are not affected, they can often breathe (without a respirator) and swallow (saliva). But there is no purposeful, reproducible, interactive, awareness. There is some controversy within the scientific medical literature regarding the characterization and diagnosis of persons in a persistent vegetative state. Highly competent, scientifically based physicians using recognized measures and standards have deduced, within a high degree of medical certainty, that Theresa is in a persistent vegetative state. This evidence is compelling.

Terri is a living, breathing human being. When awake, she sometimes groans, makes noises that emulate laughter or crying, and may appear to track movement. But the scientific medical literature and the reports this GAL obtained from highly respected neuro-science researchers indicate that these activities are common and characteristic of persons in a persistent vegetative state.

In the month during which the GAL conducted research, interviews and compiled information, he sought to visit with Theresa as often as possible, sometimes daily, and sometimes, more than once each day. During that time, the GAL was not able to independently determine that there were consistent, repetitive, intentional, reproducible interactive and aware activities. When Theresa's mother and father were asked to join the GAL, there was no success in eliciting specific responses. Hours of observed video tape recordings of Theresa offer little objective insight about her awareness and interactive behaviors. There are instances where she appears to respond specifically to her mother. But these are not repetitive or consistent. There were instances during the GAL's visits, when responses seemed possible, but they were not consistent in any way.

This having been said, Theresa has a distinct presence about her. Being with Theresa, holding her hand, looking into her eyes and watching how she is lovingly treated by Michael, her parents and family and the clinical staff at hospice is an emotional experience. It would be easy to detach from her if she were comatose, asleep with her eyes closed and made no noises. This is the confusing thing for the lay person about persistent vegetative states.

Theresa's neurological tests and CT scans indicate objective measures of the persistent vegetative state. These data indicate that Theresa's cerebral cortex is principally liquid, having shrunken due to the severe anoxic trauma experienced thirteen years ago. The initial oxygen deprivation caused damage that could not be repaired, and the brain tissue in that area continued to devolve. It is noteworthy to recall that from the time of her collapse, and for more than three years, Theresa did receive active physical, occupational, speech and even recreational therapy. There is evidence early in her records of care that she said "no" during physical therapy session. That behavior did not recur and was not further referenced.

In recent months, individuals have come forward indicating that there are therapies and treatments and interventions that can literally re-grow Theresa's functional, cerebral cortex brain tissue, restoring part or all of her functions. There is no scientifically valid, medically recognized evidence that this has been done or is possible, even in rats, according to the president of the American Society for Neuro-Transplantation. It is imaginable that some day such things may be possible; but holding out such promises to families of severely brain injured persons today may be a profound disservice.

In the observed circumstances, the behavior that Theresa manifests is attributable to brain stem and forebrain functions that are reflexive, rather than cognitive. And the substantive difference according to neurologists and neurosurgeons is that reflexive activities of this nature are neither conscious nor aware activities. And without cognition, there is no awareness. (Descartes addressed this in his proposition that it is our awareness, our consciousness that defines our being: "Cogito, ergo sum". This logic would imply that unless we are aware and conscious, we cease to be.)

By all measures in the literature, Theresa has beaten the odds in terms of surviving her persistent vegetative state condition. While younger persons fare better than older victims, life spans rarely, according to the American Academy of Neurology, exceed ten years following the onset of the condition. Persons who have been comatose have worse

outcomes than those who have not. But Theresa has also far outlived any documented periods from which persons in persistent vegetative states have emerged in any functional capacity. The reasonable degree of medical certainty associated with her diagnosis and prognosis is very high.

Overcoming the Enmity and Disagreement Regarding the Medical Outcome

The parties cooperated completely with the GAL during the thirty day investigation, analysis and report preparation. The issue of feasibility and value, raised in the court charge, and discussed throughout this report, provided the basis for very serious discussions among the parties regarding an agreement to pursue an alternative process in order to resolve the disputes in this matter and gain closure for Theresa.

During the final days of this investigation, an agreement, designed and titled a "platform of understanding" for an agreement in principle, was sculpted. Elements of the platform were acceptable and there was preliminary and contingent agreement in principle to the intent and much of the content of the drafts. All three parties, the Schindlers, Michael Schiavo, and the Office of the Governor, through their respective attorneys, participated actively in this process. The agreement was based, in good part, on the trusting relationship that evolved between the GAL and the parties during the investigation. It was expected that the parties would make a joint request to the court to allow and facilitate the agreement to be carried out.

The evening before the deadline for the submission of this report, the negotiations surrounding the agreement broke down, and the parties were not able to achieve what would have been an agreement in principle to engage in a new and different process. The outline of this agreement is in Appendix I.

Summary of Guardian Ad Litem Recommendations

Restatement of Questions and Recommendations

1. Should the Governor lift the stay that he previously entered relative to Theresa Schiavo's feeding tube?

a. Yes. The Governor should lift the stay, if valid, independent scientific medical evidence clearly indicates that Theresa has no reasonable medical hope of regaining any swallowing function and/or if there is no evidence of cognitive function and no hope of improvement.
b. No. The Governor should not lift the stay if valid, independent scientific medical evidence clearly indicates that Theresa has a reasonable medical hope of regaining any swallowing function and/or if there is evidence of cognitive function with or without hope of improvement.

2. Is there feasibility and value in swallowing tests and swallowing therapy given the totality of circumstances?
    a. Yes. There is feasibility and value in swallowing tests and swallowing therapy being administered if the parties agree in advance as to how the results of these tests will be used with respect to the decision about Theresa's future. If the parties do not agree in advance as to how the tests will be used, then the court must be prepared to once again make a final judgment on the matter. Given the history of the case, this would not, in and of itself, assure a resolution, and is not, therefore, deemed either feasible or of value to Theresa Schiavo without prior agreement.

The GAL concludes from the medical records and consultations with medical experts that the scope and weight of the medical information within the file concerning Theresa Schiavo consists of competent, well documented information that she is in a persistent vegetative state with no likelihood of improvement, and that the neurological and speech pathology evidence in the file support the contention that she cannot take oral nutrition or hydration and cannot consciously interact with her environment.[1]

[1] But that is not enough. This evidence is compromised by the circumstances and the enmity between the parties. Until recently, while both Michael Schiavo and the Schindlers agreed that Theresa was in a persistent vegetative state, they could not agree as to the matter of discontinuation of life support. Recently, the Schindlers have adopted what appears to be a position that Theresa is not in a persistent vegetative state, and/or that they do not support the fact that such a medical state exists at all. Yet throughout the nearly ten years of litigation, it is the issue of her ability to swallow, ingest food and

The GAL concludes that the trier of fact and the evidence that served as the basis for the decisions regarding Theresa Schiavo were firmly grounded within Florida statutory and case law, which clearly and unequivocally provide for the removal of artificial nutrition in cases of persistent vegetative states, where there is no advance directive, through substituted/proxy judgment of the guardian and/or the court as guardian, and with the use of evidence regarding the medical condition and the intent of the parties that was deemed, by the trier of fact to be clear and convincing.

The GAL concludes the Guardian Ad Litem appointment be extended until a resolution is concluded in the matter of Theresa Maria Schiavo.

The rules were adhered to and they are the laws of this state. Again, Justice Renquist in Cruzan: "But the Constitution does not require general rules to work faultlessly; no general rule can." Cruzan v. Director, MDH, 497, U.S. 261 (1990)

We remain in Theresa Schiavo's shoes. **END**

_____ 1 December 2003

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hydration, and the findings regarding any residual cognitive ability that have marked the medical substance of this dispute.

Of the Schindlers, there has evolved the unfortunate and inaccurate perception that they will "keep Theresa alive at any and all costs" even if that were to result in her limbs being amputated and additional, complex surgical and medical interventions being performed, and even if Theresa had expressly indicated her intention not to be so maintained. During the course of the GAL's investigation, the Schindlers allow that this is not accurate, and that they never intended to imply a gruesome maintenance of Theresa at all costs.

Of Michael Schiavo, there is the incorrect perception that he has refused to relinquish his guardianship because of financial interests, and more recently, because of allegations that he actually abused Theresa and seeks to hide this. There is no evidence in the record to substantiate any of these perceptions or allegations.

Until and unless there is objective, fresh, mutually agreed upon closure regarding measurable and well accepted scientific bases for deducing Theresa's clinical state, Theresa will not be done justice. There must be at least a degree of trust with respect to a process that the factions competing for Theresa's best interest can agree. To benefit Theresa, and in the overall interests of justice, good science, and public policy, there needs to be a fresh, clean-hands start.

The Schindlers and the Schiavos are normal, decent people who have found themselves within the construct of an exceptional circumstance which none of them, indeed, few reasonable and normal people could have imagined. As a consequence of this circumstance, extensive urban mythology has created toxic clouds, causing the parties and others to behave in ways that may not, in the order of things, serve the best interests of the ward.

APPENDIX I
PLATFORM OF UNDERSTANDING

Good faith efforts marked the Guardian Ad Litem's investigation, interviews and research process. All parties were professional, civil and helpful. It is noted that the Governor's amicus brief to the federal district court served as a guidepost for the GAL's crafting of the platform. In that amicus brief, the Governor implied the importance of obtaining valid, scientifically-based medical information in order to address certain unresolved matters affecting Theresa. The platform that was developed remains a template that can afford the parties a vehicle for achieving a common ground upon which to resolve the central disputed matters that have precluded closure for Theresa Schiavo. Perhaps more time is needed. The elements of the platform of understanding, as last discussed are presented below.

As of the deadline for submission of this report, the parties are deeply engaged in the vicissitudes of a constitutional challenge to the law that afforded the Governor the authority to stay the removal of Theresa's artificial feeding tube. The parties have had little or no opportunity or inclination, during the nearly ten years of legal hostilities, to effectively seek an alternative approach to their dispute. As a consequence, uncertainties remain on all sides of the issue. And there is now a third side: the Governor.

The constitutional challenge may take weeks, if not months to wind its way through the Florida circuit, appeals and supreme court processes. The Governor's involvement has added a new and unexpected dimension to the litigation. It is reasonable to expect that the exquisite lawyering will continue, and the greatly enhanced public visibility of the case may increase the probability of more litigation, more parties entering as intervenors, and efforts to expand the case into federal jurisdiction.

Given this scenario, it is possible that continued delay could afford the Florida Legislature the opportunity to amend certain provisions of F.S. 765 to make the law more consistent with the majority of states that require written advance directives. The GAL

believes this would be unfortunate. But were this to occur before the case resolved in the courts, it is possible that the evidentiary basis used in Theresa's previous cases would become unacceptable, and new litigation could arise around a new law's application. In this scenario, the litigation process could continue for months, if not years. This would leave Theresa in the continued netherworld of the unresolved, unless Mr. Schiavo determined that he would no longer pursue the matter.

In the alternative, the constitutional challenge could be addressed expeditiously by the court system, and in the event the law is deemed unconstitutional by the circuit court and affirmed at the district court of appeal and the supreme court, the entire process could end there. In this scenario, and given the well articulated position of the majority of the U.S. Supreme Court, it is possible that the case would not be accepted for review. It would be a good example, given the opinions in Cruzan, to leave matters such as this to the states and their legislative and judicial processes.

That scenario, if played out with reasonable speed, would lead to a final determination that Theresa's artificial nutrition should be terminated. For the third time, she could have the tube clamped or removed. She would then die within a week to ten days. Unless, some new legal maneuver intervened again – resulting in a new stay.

PLATFORM OF UNDERSTANDING FOR
ARRIVING AT A RESOLUTION
IN THE MATTER OF THERESA MARIE SCHIAVO
(Abandoned 30 November 2003)

All parties agree that the legal, medical and political issues surrounding Theresa Schiavo have made it difficult to come to any meeting of the minds among the parties regarding what is best for her.

All parties agree that their intention is to do what is best for Theresa.

All parties agree that the current circumstance has created the need for clarity and focus with respect to what is best for Theresa – to the extent possible, outside the press and even open court.

All parties agree that core issues persistently raised with respect to Theresa's condition that have been subject to the most consistently stated contest are:

- Whether Theresa can take nutrition and hydration orally

- Whether Theresa's neurological condition:

    - Includes cognitive functioning and/or capability

    - Provides a basis, given good science and medicine, to be improved to permit her to interact more with her environment

All parties agree that the legal process to date, while following statutory guidelines and rules of evidence, has not resulted in a conclusion that is, in the eyes of each of the parties, in Theresa's best interests;

to wit: those advocating for her rights to privacy and to die according to her wishes have not been successful in reaching closure; and

those advocating for her right to live, regardless of the nature of her illness, injury, disability or condition, have not been successful in excluding termination of life support as an immediate possibility.

In the informed opinion of the GAL, following the directive guidelines of the Court, no "feasible and valuable" recommendations can be made that will be in Theresa's best interests and best wishes until and unless there are changes in the status quo among the parties. These changes are best approached incrementally.

In order to create a common ground among the parties, essential to feasibly and valuably addressing the best interests of Theresa, the parties agree in principle as follows:

1. The GAL is accepted and trusted by all the parties as having clean hands and acting exclusively in the interests of Theresa.

2. The GAL's judgment regarding the best interests of Theresa and his ability to objectively, fairly, scientifically and caringly represent these interests is accepted by all the parties.

3. The GAL will select competent, neutral, clinical specialists to make a formal determination about the feasibility and value of swallowing tests and therapy for Theresa. The specialists' identities will be kept confidential from the public. The specialists' determination will have value to the process of gaining a common and agreed-upon understanding among the parties.

4. The GAL will select competent, neutral, clinical specialists to conduct appropriate examinations and tests to make a formal determination about neurological capacity and prognosis. The specialists' identities will be kept confidential from

the public. The specialists' determination will have value to the process of gaining a common and agreed-upon understanding among the parties.

5. The GAL should be permitted and authorized to move forward with a plan, designed to gain the data regarding swallowing tests/therapy and neurological capacity in a manner consistent with items 3 and 4, above, with and through the advice and input of the parties' counsels and the Court.

6. The parties agree in principle to establish in advance, parameters for their respective actions based upon the outcomes of the examinations and tests. These parameters will be developed, through the auspices of the GAL, within 10 days of the presentation of this report to the Governor, and said parameters, agreed upon by the parties, shall serve as the predicate for proceeding with the initiation of the testing and examination.

7. The successful recruitment and deployment of the clinical experts to perform the exams will be under the direction, supervision and discretion of the GAL, with advisement proffered to the attorneys for each of the parties.

8. Barring unforeseen events, the recruitment, deployment and reporting to the parties on the results of the tests will occur within 45 days of the specification referenced above in item 6 regarding the parameters.

9. In fairness, and because of the significant public policy issues involved, the costs associated with the recruitment and deployment of experts to perform the examinations and tests should be born by the State.

10. The parties respectfully request that the Court accept and honor this understanding in the interests of justice and with the expectation of achieving a feasible and valuable solution in a complex and challenging matter that has acquired a high level of public policy significance.

In the event the GAL is unable to achieve agreement on a matter, the issue will either be respectfully set aside, with the acquiescence of the parties, or, if it is deemed to be of such a critical and vital nature, it may serve to stall or terminate the good faith process. At that juncture, the GAL will report on the failure of the process and the reason for the impasse.

Within ten days of the presentation of this report, the GAL will provide the Governor and the Court with a written status update along with the details of an implementation plan.