STATE OF MICHIGAN
COURT OF APPEALS

IN RE AMB, a minor

COA #: 218869
LC #: 99-375617

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PROOF OF SERVICE

I verify that I served a copy of the foregoing document upon all attorneys of record of all parties to the above cause by First Class Mail to them at their record addresses on June 26, 01.

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AMICUS CURIAE MICHIGAN PROTECTION AND ADVOCACY SERVICE, INC.'S

BRIEF ON APPEAL

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INTRODUCTION

> ... The decision to accept or reject life-sustaining treatment has no equal. We enter this arena humbly acknowledging that neither law, medicine nor philosophy can provide a wholly satisfactory answer to this question.
>
> To err either way has incalculable ramifications. To end the life of a patient who still derives meaning and enjoyment from life or to condemn persons to lives from which they cry out for release is nothing short of barbaric. If we are to err, however, we must err in preserving life.

In re Martin, 450 Mich 204, 208; 528 NW2d 399 (1995).

With those words the Michigan Supreme Court entered the jurisprudential arena in which this Court now finds itself. The facts are different, but six years later the basic questions still remain. When, and under what circumstances, should Michigan courts intervene in decisions to withdraw life sustaining equipment? As with *Martin*, the case before this Court has no "wholly satisfactory answer." This Court can only deal with the facts before it.

Michael Martin lived. Here, though, Allison M. Bittenbender [Allison] died before this case received any judicial review of a referee's decision, and without the voice or the opinion of her mother Kitty Bittenbender [Ms. Bittenbender] being heard. Notwithstanding this tragedy, this Court has invited not only the litigants, but amici curiae including Michigan Protection and Advocacy Service, Inc. [MPAS] to review the judicial circumstances surrounding her death, and to contribute to the development of legal doctrine to prevent such injustices from happening in the future. MPAS humbly accepts its responsibility to speak for its constituents as amicus curiae.

The case now before this Court seeks input into several areas. These include *defining* the balance of power between the state, the patient, the patient's parents and medical professionals; *describing* the applicable due process standards; and *prescribing* the applicable decision making standards. MPAS now submits its input, noting as did the *Martin* Court, that "[i]f we are to err, however, we must err in preserving life." *Id.*

ARGUMENT SUMMARY

MPAS makes four arguments. The arguments are:

1. Michigan courts should strictly construe statutes and case law to protect the lives of those who are the subjects of life support withdrawal petitions. Michigan's interest in preserving life permits its courts to hear and decide petitions seeking the withdrawal of an infant's life sustaining equipment, whether filed by a parent, family member, medical professional or state agency. The term "treatment" should be defined to include the withholding of life sustaining treatment or equipment.[1]

2. Parents have a fundamental liberty interest in raising their children. A court decision authorizing the removal of an infant's life sustaining equipment is tantamount to terminating the parents' right to raise their child. If it is alleged that a parent is mentally incompetent to make medical decisions for the child, the parent is entitled to the same full due process protection and procedures provided in a parental rights termination hearing; and to receive notice and an opportunity to be heard in all subsequent court actions involving the child's medical care.[2]

3. When a surrogate decision maker is required for an infant using or in need of life sustaining medical equipment, the "best interests" standard should be used along with the "clear and convincing evidence" standard. It is never clearly and convincingly in an infant's best interests to terminate life

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[1] This argument sets the policy considerations essential to this Court's decision on all questions presented, and addresses the issues raised in Question Cluster III, B, C (first bullet), and E. This Court's Order, dated April 2, 2001, which contains the Question Clusters in their entirety, is attached as Exhibit #1.

[2] This argument addresses the issues raised in Cluster I, B, and touches on the issues raised in Cluster II, B. See Exhibit #1.

sustaining equipment when the infant is neither terminally ill nor in a persistent vegetative state.[3]

4. The surrogate's decision making powers should not be usurped by the opinions of medical professionals that continued medical treatment would be "futile." The theory of "futile care" should not be used in this case, where Allison was neither terminally ill nor in a persistent vegetative state.[4]

Applying these arguments to the facts presented[5], MPAS argues that, assuming jurisdiction, the trial court should hear and decide the case; Ms. Bittenbender's fundamental right as Allison's mother to make or participate in making medical decisions for Allison were denied her; and that the decision by the referee authorizing the removal of Allison's life sustaining equipment was not supported by clear and convincing evidence that Allison was terminally ill or in a persistent vegetative state. The trial court decision should be reversed, with instructions on how future cases are to be processed in the absence of Legislative intervention.

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[3] This argument addresses the issues raised in Cluster III, A. See Exhibit #1.

[4] This argument addresses the issues raised in Cluster III, A, B, D E. See Exhibit #1.

[5] MPAS acknowledges that this Court, in Cluster III, C (fourth bullet) invited comment on jurisdictional issues, particularly related to the *second* petition (submitted by the FIA) seeking the trial court's order to remove Allison's life support. MPAS chose not to address the jurisdiction issue because its expertise lies in the policy and procedure areas addressed in this Brief. MPAS argues in Issue II that Ms. Bittenbender's right as Allison's mother to make or participate in making the decision to remove or leave Allison's ventilator in place belonged to Ms. Bittenbender until or unless that trial court properly found her incompetent to make treatment decisions for Allison. Implicit in this argument is that the second petition by FIA should not have been heard or decided by the referee at the time or in the way it was, because Ms. Bittenbender was ignored and her rights were bypassed. However, MPAS does not believe that the "second petition" question asked in Cluster III, C is focused on the process arguments MPAS makes, but rather on jurisdictional issues raised by the *nature* of the second petition when it "changed the focus of the proceedings from protecting AMB to ending her life."

In a related vein, MPAS recognizes that this Court could hold that the second petition lacked jurisdiction, thereby relieving this Court of any duty to consider the policy and procedural issues which form the core of MPAS' Brief. But if the jurisdictional argument fails, then the issues MPAS addresses here are central to this Court's consideration, and MPAS would be remiss in its duty as amicus curiae if it failed to address them.

STATEMENT OF INTEREST OF AMICUS CURIAE

MPAS is the Michigan entity charged with implementing the federal protection and advocacy (P&A) statutes enacted to protect the legal rights of people with disabilities.[6] The P&A statutes express Congress' belief that disability is a natural part of the human condition, that people with disabilities have value, and that their voices -- regardless of legal competence or the severity of impairment -- must be heard. MPAS asks this Court to let it be their voice here as its constituents have a direct stake in this Court's decision concerning when, under what circumstances, and with what due process protection, minors with disabilities on life sustaining medical equipment may have that equipment removed.

MPAS' activities protect persons with developmental disabilities such as cerebral palsy, mental retardation, multiple sclerosis and others that arise during one's developmental years; persons who have an emotional or mental illness; and persons who are disabled later in life by illness, injury, and/or aging. The P&A statutes empower MPAS to pursue legal, administrative, and other remedies to vindicate the rights of its constituents. 42 USC 6042(a)(2)(A)(1); 42 USC 10805(a)(1)(B); 29 USC 794e(f)(3). Congress has given MPAS a special duty to protect people with disabilities from abuse, neglect, and life-threatening actions, and has given MPAS provisions to secure confidential information and pursue legal action without guardian consent or cooperation. 42 USC 6042(a)(2)(B) and (a)(2)(G)(iii); 42 USC 10805(a)(1)(A) and (a)(4)(C); 29 USC 794e(f)(2).

In the exercise of its duties, MPAS is guided by the principles expressed by Congress:

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[6] The statutes are the Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 USC 6000 *et seq*, the Protection and Advocacy for Mentally Ill Individuals Act of 1986, 42 USC 10801 *et seq*, and the Protection and Advocacy for Individual Rights Act of 1992, 29 USC 794e(a). Pursuant to MCL 330.1931, MPAS is the Michigan agency designated to represent the rights of persons protected by these laws.

- persons with disabilities have "legal and human rights," including the right to due process of law prior to the deprivation of fundamental rights
- persons with disabilities, "notwithstanding their severe disabilities" have "capabilities, competencies, and personal needs and preferences"
- persons with disabilities, to the "maximum extent feasible," should "make decisions for themselves"
- persons with disabilities are entitled to "exert control and choice over their own lives"

42 USC 6000(a); 42 USC 6001(6).

MPAS' mission is to advance the dignity, equality, self-determination, and expressed choices of individuals. To that end, and in harmony with Congress' core policy, MPAS has been significantly involved in the legal, legislative, administrative, institutional, and civic processes impacting on people with disabilities and their rights.

MPAS has actively participated in Michigan appellate cases focused on the legal protection available to people with disabilities in actions seeking the withdrawal of life sustaining equipment[7] and the imposition of involuntary sterilization,[8] guardianships [9] and involuntary hospitalization.[10]

MPAS' decades of experience in protecting the rights of persons with disabilities renders MPAS uniquely qualified to assist this Court in determining and defining the rights of Allison and

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[7] *In re Martin, supra.*

[8] *Mich. Pro. & Adv. Svc. v Kirkendall*, 841 F Supp 796 (ED Mich, 1993), *Mich. Pro. & Adv. Svc. v Kirkendall*, 863 F Supp 482 (ED Mich, 1994). *In re Wirsing*, 214 Mich App 131; 542 NW2d 594 (1996) rev'd 456 Mich 467; 573 NW2d 251 (1998). MPAS' Supreme Court *Wirsing* Brief was selected by the Thomas Cooley Law School Law Review as one of three outstanding briefs submitted to the Michigan Supreme Court in the 1997-1998 term.

[9] *Matter of Neal*, 230 Mich App 723; 584 NW2d 654 (1998).

[10] *In re KB*, 221 Mich App 210; 562 NW2d 208 (1997).

the thousands of people who could live or die by the Court's decision in the years to come. MPAS, as a result of its history of representing the interests of persons with disabilities and its first-hand knowledge of the devaluation and vulnerability of such persons, has grave concerns about the implications of the decision to be made by this Court and appreciates the complexity of the issues presented. MPAS' constituents include thousands of Michigan citizens who were born with severe cognitive impairments, often with associated health problems, and who have never been legally competent or capable of exercising "informed consent." Termination of life support for legally incompetent persons -- children or adults -- raises constitutional, ethical, and societal concerns of the highest magnitude. Michigan's community of adults and children who have disabilities need and deserve a powerful voice in this appeal to be sure that the strongest possible due process system is devised to insure that their fundamental right to life is protected.[11] [12]

STATEMENT OF FACTS

MPAS adopts and incorporates the fact statements submitted by Appellant Allison Bittenbender as stated in her Application for Leave to Appeal,[13] and in her Supplemental Brief.[14]

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[11] Letters from disability rights associations or agencies supporting MPAS' positions taken in this Brief are attached as Exhibit #2.

[12] MPAS acknowledges and appreciates the contributions MPAS interns Amy Ginn and Charles Guiterrez have made to this Brief.

[13] Dated February 7, 2000 pp 1-9. A copy of these pages is attached as Exhibit #3.

[14] Dated June 14, 2001 pp 2-4. A copy of these pages is attached as Exhibit #4.

ARGUMENT

ISSUE I: IN LIFE SUPPORT CASES, COURTS SHOULD BALANCE THE STATE'S INTEREST IN PRESERVING LIFE AGAINST THE INDIVIDUAL'S INTERESTS; SHOULD ACCEPT PETITIONS FROM ALL INTERESTED PERSONS OR ENTITIES INCLUDING STATE AGENCIES; AND SHOULD HOLD THAT "TREATMENT" INCLUDES REMOVING LIFE SUPPORT EQUIPMENT.[15]

This issue sets out the State's interest in preserving life, and how that interest is balanced against the individual's right to exercise informed consent. MPAS explains that the State's interest allows both individuals and state agencies to petition for judicial determination of the propriety of removing life support equipment.[16] Defining the term "treatment" to include removing life support systems clarifies the significance of the doctrine of informed consent and the need to preserve life when informed consent must be exercised by a surrogate decision maker.[17]

The broad questions now before this Court are predicated on the assumption that the state has an interest that, when balanced against the individual, allows the state to take over, or to allow others to take over decision making functions for the person who cannot decide for him or herself. Indeed, in this case it was the Family Independence Agency [FIA], an entity under the control of the executive branch, that petitioned for the withdrawal of Allison's life support equipment. Courts

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[15] This argument sets the policy considerations essential to this Court's decision on all questions presented, and addresses the issues raised in Cluster III, B, C (first bullet), D and E. See Exhibit #1.

[16] It is the *fact* of court access that is important here. MPAS does not assume that all persons or entities who seek court intervention in life support termination cases necessarily do so seeking to end the use of life support. Indeed, some corporate or public guardians seek court guidance in all life support cases because they [the guardians] do not know their clients, or their clients' wishes or desires well enough to make life and death decisions for them. The courts should be open to all interested individuals, guardians and public agencies so that petitions to prevent the withdrawal of life support systems also may be presented to and decided by the courts. As this Issue argues, this court role is essential to the State's interest in preserving life.

[17] See n 5, *supra*.

reviewing cases involving the termination of life support have used various approaches to assess and balance the state's interests against the individual's interests. It is helpful to review the different interests which have been identified.

THE RIGHTS OF THE INDIVIDUAL

Two legal doctrines generally provide that a competent person has the right to control his or her medical treatment. The doctrines are the common law right of informed consent and the individual's substantive "liberty" interest under the Fourteenth Amendment, Const. Am XIV. In addition, MPAS believes that additional individual rights are implicated when a guardian or surrogate seeks to exercise decision making: the individual's substantive due process interest in "life" under the Fourteenth Amendment and the individual's right to procedural due process.

The Common Law Right of Informed Consent

The common law doctrine of informed consent[18] allows a legally competent person to choose to accept or reject medical treatment, including life support. Informed consent has been defined as:

> [t]he right of the patient to determine the nature of his or her own medical care. This value reflects our society's long-standing tradition of recognizing the unique worth of the individual. We respect human dignity by granting individuals the freedom to make choices in accordance with their own values. The principle of autonomy is the moral basis for the legal doctrine of informed consent, which includes the right of informed refusal.

Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of Dying*, 7 (1987), cited in *In re Gardner*, 534 A2d 947, 950 (Me, 1987). Even this powerful right of the competent individual is not absolute and must be balanced against the state's interests. *Cruzan v Harmon*, 760 SW2d 408, 419 (Mo, 1988).

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[18] This right also may be called the "right to refuse treatment," the "right to self-determination," or the "right to autonomy."

The Fourteenth Amendment "Liberty" Interest

Some courts have relied upon the constitutional right of privacy, but the U.S. Supreme Court has favored and recognized the individual's liberty interest under the Due Process Clause of the Fourteenth Amendment:

> The Fourteenth Amendment provides that no State shall "deprive any person of life, liberty, or property, without due process of law." The principle that a *competent* person has a constitutionally protected liberty interest in refusing unwanted medical treatment may be inferred from our prior decisions.

Cruzan v Director, Missouri Dept. of Health, 497 US 261, 280; 110 S Ct 2841; 111 L Ed 2d 224 (1990) (emphasis added). In *Cruzan*, however, the Court cautioned that "we do not think the Due Process Clause requires the State to repose judgment on these matters with anyone but the patient herself." *Id* at 497 US 286. Therefore, a guardian or other surrogate does not possess any liberty interest on their own or on their ward's behalf under the Constitution.

The Fourteenth Amendment Interest in "Life"

MPAS is concerned that an individual's decision making rights, whether expressed in common law or constitutional terms, often are too easily transferred to a surrogate decision maker without adequate consideration of the constitutional and practical implications *to the ward* of this substitution. Not only do guardians not possess constitutional interests, but a state agency's decision acting on its own, or a state-appointed guardian's decision concerning termination of a ward's life support implicates the *ward's* constitutional interests. Specifically, the state or third party's action implicates not only the ward's "liberty" interest but also the ward's substantive interest in "life" under the Fourteenth Amendment. The ward cannot be deprived of these interests absent the strongest procedural protection.

THE STATE'S INTERESTS

The primary legal check on the individual's decision making rights are the State's interests, in particular the State's interest in preserving life. In *Matter of Conroy*, 98 NJ 321; 486 A2d 1209, 1233 (NJ, 1985), the New Jersey Supreme Court reviewed the State's interests:

> Whether based on common-law doctrines or on constitutional theory, the right to decline life-sustaining medical treatment is not absolute. In some cases, it may yield to countervailing societal interests in sustaining the person's life. Courts and commentators have commonly identified four state interests that may limit a person's right to refuse medical treatment; preserving life, preventing suicide, safeguarding the integrity of the medical profession, and protecting innocent third parties.

Id., 486 A2d at 1233.

The State's interests are strong when an incompetent person's life support is at issue. But other state interests in addition to the *Conroy* Court interests are implicated when the decision whether to terminate life support is going to be made by a guardian or surrogate decision maker.

The State's interest in preserving life becomes *stronger* when the person who is using the life support systems is not only not competent, but also not able to voice a preference in the face of a specific medical condition and a specific range of treatment options. The State's interests become still stronger when a State-appointed guardian or state agency is seeking permission to terminate life support. These interests include protecting the incompetent person from potential conflicts of interest and insuring procedural due process, and the interest in fulfilling its *parens patriae* duty to safeguard infants and incompetent persons. When a guardian or state agency is seeking to exercise the decision making power of the individual, the State's and the individual's interests are no longer in opposition but are largely complementary.

The State's *Parens Patriae* Interest

The law long has recognized that state courts owe a special duty to persons who are legally incompetent. A court's authority is "at its widest reach" when acting to protect the personal or property rights of an incompetent person. *In the Matter of AW*,637 P2d 366, 375 (Col, 1981). The court's power is "plenary and potent to afford whatever relief may be necessary" to protect the interests of the incompetent person. 27 *AmJur2d Equity* 69, p. 592 (1969).

Thus, under the *parens patriae* doctrine, the State is obligated to exercise independent power to protect legally incompetent persons, especially when they are the subjects of court petitions. As the Michigan Supreme Court has noted, this duty has deep roots in the common law:

> [O]ne non compos mentis is incapable of acting to protect his rights from the rapacity of those instituting suits against him. At Common Law, the rights of persons non compos mentis were peculiarly under the protection of the King....But in this country,...courts exercising equitable powers are charged with the duty of protecting the rights of [incompetent persons].

Cohen v Home Life Insurance Co, 273 Mich 469, 476; 263 NW2d 857 (1935).

The State's Interests as Expressed in the Patient Advocate Act

Courts confronted with requests to authorize termination of life support have been vexed by legislative bodies' failures to establish an orderly scheme for these difficult cases. As Judge Sawyer noted in his partial concurrence in *In re Rosebush*, 195 Mich App 675; 491 NW2d 633 (1992) :

> Because of the complex and sensitive nature of issues that are related to the removal of life-support systems, ... courts [have] urged that judicial policy making give way to the legislative process in order to insure that the interests of the constituency are served.

Id., at 693-94.

Michigan's Legislature *has* directly confronted the life support termination issue, and its acts and underlying policies are entitled to substantial judicial deference.[19] In 1990, Michigan enacted the Designation of Patient Advocate Act [Act], now codified at MCL 700.5506-5513; MSA 15506-15513. The Act enables a person to execute a written designation which (1) specifies the person's future care and medical treatment desires and (2) appoints a surrogate decision maker (patient advocate) to carry out the person's desires should the person become unable to participate in medical care decisions. The Act, particularly its revocation provisions, expresses powerful indices of Michigan's legislative policy that people who become disabled retain the broad right to change their minds about previously expressed medical care intentions. This is an obvious expression of Michigan's interest in both protecting self-determination *and* preserving life.[20]

Simply put, the Act declares that a person who is currently ill, injured, or disabled has the final say -- expressed through any method of communication -- about his or her life-sustaining treatment. This remains the person's right, even if the person previously expressed a contrary desire, and even if the person lacks legal competence or the ability to participate in medical decisions. Michigan has the right to insist upon specificity, and the Act does so.

BALANCING THE INTERESTS

The Act's recognition of the dispositive nature of the individual's current desire, even if

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[19] The Act could provide the *exclusive* means by which a person can express intentions to control later decision making, as Michigan courts had not recognized a common law right to make such advance decisions prior to the enactment of the Act. See *Gregory v. Kurtis*, 108 Mich App 443; 310 NW2d 415 (1981)(statute is exclusive remedy for enforcement of a right not recognized by common law). As the U.S. Supreme Court's *Cruzan* decision suggests, States have wide latitude in selecting procedures and safeguards to use to protect the State's interest in preserving life, and a State's decision to prescribe by statute the procedures which must be followed is valid. Even if the Act is not exclusive, it is of prime importance in determining public policy in Michigan.

[20] The Act, like the procedural due process model employed by courts in involuntary sterilization cases, seeks to achieve a balance which allows an incompetent person the ability to exercise his or her rights while protecting against overreaching.

expressed without a writing or without verbal language, stands in stark contrast to the decision making ability of the patient advocate. Under the Act, a patient advocate can decide to forgo life-sustaining treatment for an individual who is incapable of expressing a current desire only if the individual had stated in a "clear and convincing manner" that the advocate has authority and that the individual knew the decision would result in death. MCL 700.5509(1)(e); MSA 27.15509(1)(e). Any standard devised for individuals who cannot or will not execute a valid designation must at least meet, if not exceed, the standards set out in the Act.

For those people born with developmental disabilities which likely will result in their lifelong legal incompetence, Michigan's strong interest in preserving life, its *parens patriae* interest in protecting those who are legally incompetent, and its interest in protecting the concomitant constitutional interests of its disabled citizens to "life" and "liberty" cannot be overstated. In such a case the State's and the individual's interests in life are at their strongest and are complementary.

MPAS urges this Court to approach this case with the strongest possible caution and with due notice of the implicit and explicit potential the case has to devalue the worthiness of the lives of persons with severe disabilities. As the court stated in *Conroy*:

> We do not believe that it would be appropriate for a court to designate a person with authority to determine that someone else's life is not worth living simply because, to that person, the patient's "quality of life" or value to society seems negligible. [To do so] would create an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps.

Conroy, supra, at 486 A2d 1233.

The balance between the person's and the state's interest likewise was evaluated in *Cruzan, supra*. The Court noted Missouri's claim that it had a legitimate "interest in the protection and preservation of human life,"*Id.*, at 280, and agreed that "there can be no gainsaying this interest." *Id.*

The Court then observed that:

> [I]n the contest presented here, a State has more particular interests at stake. The choice between life and death is a deeply personal decision of obvious and overwhelming finality. We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements."

Id., at 281.

The Court balanced that interest against an individual's 14th Amendment liberty interests:

> It cannot be disputed that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment. Not all incompetent patients will have loved ones available to serve as surrogate decisionmakers. And even where family members are present, '[t]here will, of course, be some unfortunate situations in which family members will not act to protect a patient.' [Citation omitted]. A State is entitled to guard against potential abuses in such situations.

Id.

The Court then held that, indeed, Missouri did have the right to choose a route or process by which such claims could be tested by the state within its judicial system. The Court stated:

> We do not think a State is required to remain neutral in the face of an informed and voluntary decision by a physically-able adult to starve to death.
>
> . . .
>
> ... We believe Missouri may legitimately seek to safeguard the personal element of this choice through the imposition of heightened evidentiary requirements. ... A state is entitled to guard against potential abuses in such situations. Similarly, a State is entitled to consider that a judicial proceeding to make a determination regarding an incompetent's wishes may very well not be an adversarial one... Finally, we think a State may properly decline to make judgments about the "quality" of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interest of the individual.

Id., at 280-282.[21]

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[21] This holding, that the state may "safeguard the personal element of this choice" through "heightened evidentiary requirements," necessarily included the right to:

Michigan's Act clearly articulates the policy of Michigan regarding the safeguards required to protect the State's complementary interests in the preservation of life, the assurance that persons with disabilities retain their liberty interest in exerting control over their lives, and the protection of incompetent persons from over-reaching:

> Irrespective of a previous expressed or evidenced desire, a current desire by a patient, to have provided, and not withheld or withdrawn, a specific life-extending care, custody, or medical treatment *is binding* on the patient advocate, if known by the patient advocate, *regardless of the then ability or inability of the patient to participate in care, custody, or medical treatment decisions or the patient's competency.*

MCL 700.5511(1), MSA 27.15511(1) (emphasis added).

Significantly, Michigan's Act recognizes that even persons who are legally incompetent may still be able "to participate in ... medical treatment decisions." MCL 700.5508(2); MSA 27.15508(2).

ACCESS TO THE COURTS

When the State's interests are balanced against or with the petition subject's interests, Michigan policy favors strong protection of the subject's decision making rights at every point. The State's interest in preserving life, here Allison's life, is not just strong, but compelling. It is consistent, then, to permit wide court access to potentially interested persons or agencies, including the FIA, to petition the court for guidance in end of life decisions.

Rosebush, supra, takes the position that "the public policy of judicial nonintervention ... extends to decisions concerning the medical treatment of incompetent persons and minors." (Citation omitted). *Id.*, at 687. However, the *Rosebush* Court understood that impasses or disputes

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> ... [P]lace an increased risk of erroneous decision on those seeking to terminate an incompetent individual's life-sustaining treatment... In sum, we conclude that a State may apply a clear and convincing evidence standard in proceedings where a guardian seeks to discontinue nutrition and hydration of a person diagnosed to be in a persistent vegetative state. *Id.*,at 283.

over treatment might occur, and similarly anticipated that guardians are required for children whose parents are unable to act as decision makers. *Id.*, at 683, n 5. *Rosebush* permits court involvement in life support termination "when an impasse is reached" in the decision making process, *Id.*, or "when the parties directly concerned disagree about threatment, or other appropriate reasons are established for the court's involvement." *Id.*, at 687.[22]

Rosebush's holding on this point is consistent with Michigan's interest in preserving life. An interested party, be it parent, family member, medical professional, care provider or state agency, should be encouraged to seek court intervention when an infant's life is at stake, and life support issues impacting on that life are in play. One can envision circumstances where an interested party like the FIA, fearing the unilateral withdrawal of an infant's life support, would choose to seek court intervention to stop the life support termination. The intervention should be encouraged.

DEFINING THE WORD "TREATMENT"

The term "treatment" may include situations where it is proper to withhold treatment. The authority to consent to medical treatment does include the power to consent to withholding or withdrawal of medical care, but only if proper procedural safeguards are in place.

"Clearly, it is one thing to order the provision of essential medical treatment in the hopes of prolonging life, and yet another to refuse treatment which may result in the termination of life." *In re K.I., B.I., and D.M.*, 735 A2d 448, 462 (DC App, 1999). While recognizing this distinction, courts have tried to avoid having medical decisions made by default. "Although it may be argued

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[22] While arguing here that *Rosebush* permits intervention in cases like Allison's, MPAS also argues in Issue III, *supra*, that *Rosebush's* nonintervention position does not survive judicial scrutiny when balanced against the legislative policy of the Act or the holding in *Martin, supra* when the factual reality is that the minor or incompetent person is neither in a persistent vegetative state nor terminally ill. The *Rosebush* child was in fact in a persistent vegetative state.

that when a patient's desires cannot be determined, life-sustaining medical treatments should be instituted or maintained, we are of the belief that such an outcome is as much a decision, by default, as any other." *In re C.A.*, 603 NE2d 1171, 1183 (Ill. App. Ct. 1992). Authority to consent to medical care has consistently been found to include the power to consent to the withholding or withdrawal of care, *Rosebush, supra*; *In re K.I., B.I., and D.M., supra*; *In re C.A, supra.*[23]

In *In re C.A.*, a state guardian petitioned the juvenile court to obtain a "do not resuscitate" (DNR) order in the terminally ill child's medical chart. The appeals court affirmed the finding that the guardian could consent to withholding life saving treatment. The court concluded that the statutory language allowed a guardian to consent to "major medical and surgical treatment:"

> [T]hese provisions support the guardian's general standing to petition the court for authority to consent to a medical judgment made by the ward's treating physicians, even when the judgment is to discontinue life-sustaining medical treatment.

Id., at 1178.

The trial court here purportedly relied on the Juvenile Code to allow withdrawal of Allison's life support. MCLA 712A.18(f); MSA 27.3178(598.18)(f) states that the court may "[p]rovide the juvenile with medical, dental, surgical or other health care, in a local hospital if available or elsewhere..." This language leaves open the possibility of consenting to withdrawal of life support in its reference to "other health care." This wording is less restrictive than the Illinois statute that while only referencing "major medical and surgical treatment" was found to include power to authorize a DNR order. *In re C.A., supra.* Michigan's informed consent doctrine, which recognizes a right to withhold or withdraw medical care as a part of the right to bodily integrity, *Martin, supra;*

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[23] But see *In re Infant C*, 37 Va Cir 351 (1995) (concluding that withholding of treatment is not included within statutory language authorizing consent to emergency surgery or medical treatment).

Rosebush, supra, further justifies construing the statute to include the authority to consent to withdrawal of treatment.

Given that the statute confers the ultimate authority to refuse treatment, thereby ending a life, it is imperative that procedural safeguards be put in place to insure that a proper surrogate decision maker exercises that authority. The cases cited above all involved children who were more clearly under the jurisdiction of the juvenile court than Allison.[24]

Even when a court declined to construe statutory medical consent authority to include withholding treatment, the infant was in "state" custody and had a state-appointed medical guardian ad litem who petitioned for the DNR order. *In re Infant C, supra.* Here, Allison did not have the required procedural safeguards in place to require that her best interests be established by clear and convincing evidence before the court authorized the removal of her ventilator.[25]

In summary, the term "treatment" as embodied in Michigan law embraces situations where it is appropriate to withhold or withdraw life sustaining treatment or equipment when proper procedural safeguards are in place. Allison Bittenbender, however, was not procedurally or appropriately protected, and thereby lost her life. Given that she was neither terminally ill nor in a persistent vegetative state, it was not clearly and convincingly in her best interests to withdraw her breathing device. This cannot be allowed to happen to another child or incompetent person.

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[24] See *In re K.I., supra*, (recognizing that K.I. was found to be neglected at a fact-finding hearing, in custody of Dept. of Human Services, and had a medical guardian ad litem);and *In re C.A., supra*, (stating that C.A. had a guardian from Dept. of Child and Family Services as well as a guardian ad litem).

[25] As with the issue of access to the court, the interpretation of the term "treatment" must embrace the panoply of options truly available for an individual. Assuming that proper safeguards are in place, a court should have the power to grant a guardian or surrogate decision maker's request to withdraw life support when an infant or incompetent person is either terminally ill or in a persistent vegetative state and is experiencing great pain or suffering.

ISSUE II: A PARENT ALLEGED TO BE INCOMPETENT TO MAKE MEDICAL DECISIONS FOR HIS OR HER CHILD IS ENTITLED TO FULL CONSTITUTIONAL DUE PROCESS TO PROTECT HIS OR HER FUNDAMENTAL RIGHT TO PARENT THE CHILD, AND TO REMAIN INVOLVED IN THE CHILD'S LIFE.[26]

REQUIRED DUE PROCESS PROTECTION

In *Rosebush, supra*, the court noted:

> It is well established that parents speak for their minor children in matters of medical treatment. [Citations omitted] Because medical treatment includes the decision to decline life-saving intervention [citation omitted], it follows that parents are empowered to make decisions regarding withdrawal or withholding of lifesaving or life prolonging measures on behalf of their children.

Id., at 683.

The Court also noted:

> Of course, where the parents of a minor child for some reason are themselves incompetent to act as surrogate decision makers, and other family members are unavailable or unwilling to act as surrogates, a guardian should be appointed to exercise the minor's rights on behalf of the minor.

Id., at 683 n 5. [citing Meisel, Alan, *The Right to Die*, 2nd Ed (New York Wiley Law Publications, 1995) Vol 2, p 417.]

Here the trial court had temporary custody of Allison because it was alleged that Ms. Bittenbender was negligent in Allison's care because she had a developmental disability and was unable to comprehend Allison's medical condition or needs. However, Ms. Bittenbender was not judged incompetent, nor had any action been taken to terminate her parental rights. The FIA filed a petition asking the court to approve the removal of Allison's ventilator. The court referee granted the petition without holding a hearing to determine Ms. Bittenbender's ability to understand

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[26] This argument addresses the issues raised in Cluster I, B and touches on the issues raised in Cluster II, B. See Exhibit #1.

Allison's medical condition. The life support hearing was held without proper notice being given to Ms. Bittenbender, without her attendance at the hearing, and without her being represented by an attorney.

A decision to terminate life supports is the functional equivalent of terminating parental rights. The Supreme Court of Nebraska, in a similar case, weighed what due process should be allowed parents in this situation. *In re Interest of Tabatha R.*, 252 Neb 687, 564 NW2d 598, (Neb, 1997). In *Tabatha*, like here, the juvenile court took temporary custody of an infant child who had serious medical problems. Her mother's parental rights were not terminated. The Department of Social Services filed a notice advising her parents that it intended to direct the hospital to remove Tabatha from life supports. The parents sought an order staying the life support removal. They asserted that an order withdrawing Tabatha's life support was tantamount to a judgment terminating their parental rights, thereby violating their constitutionally protected liberty interest in their parent-child relationship with Tabatha. The Court sided with the parents:

> **We agree that since the implementation of The Department's determination is likely to result in the infant's death and thereby sever the relationship between the infant and the parents, the juvenile court's assent is the functional equivalent of a judgment terminating parental rights.** We therefore hold that where a proceeding to obtain the juvenile court's assent to the medical services determined by the department under §43-285(1) results in the functional equivalent of a proceeding to terminate parental rights, **the same due process must be afforded in the assent proceeding as is required in a proceeding to terminate parental rights**. (emphases added.)

Id., at 605.

The court, citing *State v Suran*, 204 Neb. 546, 283 NW2d 382 (Neb, 1979), then noted that although parental rights are not absolute or inalienable, such rights do not:

> evaporate simply because [the parents] have not been model parents or have lost

> temporary custody of their child to the State. Even when blood relationships are strained, parents retain a vital interest in preventing the irretrievable destruction oft their family life. If anything, persons faced with forced dissolution of their parental rights have a more critical need for procedural protections than do those resisting state intervention into ongoing family affairs. [*Santoskey v. Kramer*, 455 U.S. 745, 753, 102 S Ct. 1388, 1394-95, 71 L Ed.2d 599 (1982).)

Id.

Applying *Tabatha* to the present case, granting the petition to remove Allison's life support resulted in terminating Ms. Bittenbender's parental rights. Thus, Ms. Bittenbender was entitled to a full hearing affording the same due process rights under Michigan law as she would have had in a parental termination proceeding. Her rights include notice of the hearing, the right to be present, the right to an attorney, and the use of the " clear and convincing evidence" standard. MCL 712A.19b *et. seq.*; MSA 27.3178(598.19(b) *et. seq.*

At a parental termination hearing, the primary question should have been whether Ms. Bittenbender had the capacity to make medical or end-of-life decisions for Allison. The clear and convincing standard would apply as it also is used in Michigan to decide competency matters under guardianship laws for individuals with developmental disabilities. MCL 330.1607(3).

There is no definitive guidance on how to decide if a parent is competent to make end-of-life decisions for her child. Meisel, supra, Vol. 1, p 138, notes that there is no single, accepted definition of incompetence to make decisions about health care. "Statutory provisions for the adjudication of competence vary widely . . .Court definitions of competency also vary."[27]

Meisel continues:

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[27] From U.S. Dep't of HEW, *Protection of Human Subjects -- Research Involving Those Institutionalized as Mentally Infirm: Report and Recommendations of the Nat'l Comm'n for the Protection of Human Subjects of Biomedical and Behavioral Research*, 43 Fed. Reg. 11, 328, 22, 345-46 (1978).

> ...[T]hough there are beginning to be signs of an emerging consensus about the meaning of and standards for determining competence and incompetence, at least in the realm of medial decision making.
>
> ... There are ... two well-accepted approaches to assessing (if not actually defining) incompetence: the general incompetence approach and the specific incompetence approach.
>
> ... The general incompetence approach has long been the dominant approach used by courts. However, it is gradually falling into disfavor, spurred by legislative changes and by litigation aimed at enhancing the rights of the mentally ill and mentally retarded ...
>
> ... Specific incompetence approaches reject the idea that incompetence is an all-or-nothing condition and instead focus on a person's ability to perform a particular task. . . under the specific incompetence approach, it does not even make sense to say that a person is incompetent; the only acceptable statement is one that is followed by an object -- that is, a person is competent or incompetent to perform x.

Id., at 138 - 144.

Applied to the present case, this would mean that a specific determination should have been made regarding Ms. Bittenbender's competency to make a medical decisions for Allison, independent of her competency in other areas.

Meisel believes that the specific incompetence approach is emerging as the predominant one. In medical decisions cases, the patient should understand information necessary to make the relevant treatment decision. He cites this Court's first *Martin* case as the best example of this approach:

> The test for determining if a person has the requisite capacity to make a decision concerning the withholding or withdrawal of life-sustaining medical treatment is whether the person (1) has sufficient mind to reasonably understand the condition, (2) is capable of understanding the nature and effect of the treatment choices, (3) is aware of the consequences associated with those choices, and (4) is able to make an informed choice that is voluntary and not coerced. [*In re*]*Martin*[, 200 Mich App 703;] 504 NW2d 917, 924 ([ ]1993). Accord [*In re*]*Martin*[, 205 Mich App 96;] 517 NW2d 749 ([ ] 1994).

Meisel, *supra* at 147.

The New Jersey Superior Court tested similar medical decision-making considerations in *In the Matter of Schiller*, 372 A2d 360 (NJ Sup Ct, 1977):

> In terms of mental capacity to consent, the test may be stated as: Does the patient have sufficient mind to reasonably understand the condition, the nature and effect of the proposed treatment, attendant risks in pursuing the treatment, and not pursuing the treatment?

Id., at 367.

Although Kitty Bittenbender is not the patient here, she is Allison's mother, her parental rights were never terminated, and she was Allison's preferred surrogate decision maker. Thus, her capacity to make an end-of-life decision for Allison should have been similarly tested.

A guardian should be appointed to act as surrogate for a child only if evidence in a due-process hearing clearly and convincingly proves that the mother is not competent to make the decision. Absent that showing, the parent should be allowed to participate fully in the due process hearing to determine the end-of-life decision for her daughter.

FUNDAMENTAL RIGHT TO PARENT

The United States Supreme Court, in *Stanley v Illinois*, 495 US 645 at 651 (1973) summarized the long recognized fundamental right parents have to raise their children.

> The Court has frequently emphasized the importance of the family. The rights to conceive and to raise one's children have been deemed "essential," *Meyer v Nebraska*, 262 US 390, 399 (1923), "basic civil rights of man," *Skinner v Oklahoma*, 316 US 535, 541 (1942), and "[r]ights far more precious. . . than property rights," *May v Anderson*, 345 US 528, 533 (1953). "It is cardinal with us that the custody, care and nurture of the child reside first in the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder." *Prince v Massachusetts*, 321 US 158, 166 (1944). The integrity of the family unit has found protection in the Due Process Clause of the Fourteenth Amendment, *Meyer v Nebraska*, *supra* at 399, the Equal Protection Clause of the Fourteenth Amendment,

> *Skinner v Oklahoma, supra*, at 541 and the Ninth Amendment, *Griswold v Connecticut*, 381 US 479, 496 (1965) (Goldberg, J., concurring).

Stanley, supra 495 US at 651.

Any allegation that a parent lacks capacity to be involved in decisions about their child's care necessarily infringes upon their fundamental right to raise their family. A state may not interfere with a fundamental right without any review, including notice and an opportunity for determination on an individual basis. To do so would violate the principle that "a person may not be deprived of his property or liberty by a state or its officials without fundamentals of procedural due process: (1) a hearing (2) before an impartial decision maker, after (3) notice ..., and (4) with an opportunity to present one's own case." *Schrank v Bliss*, 412 F Supp 28, 41 (M.D. Fla. 1976). Thus, all due process protections must be in place before another surrogate decision maker is appointed to take over these parental rights.

Michigan law requires that when a guardian is appointed to make decisions for a person with a developmental disability, such an appointment can only be made "to the extent necessitated by the individual's actual mental and adaptive limitations." MCL 330.1602(1); MSA 14.800(602(1). All due process protections to effectuate the rights of the person are required, including a hearing, MCL 330.1614 (1); MSA 14.800(614)(1); notice, MCL 330.1614(3); MSA 14.800(614)(3); right to counsel, MCL 330.1615(1); MSA 14.800(615)(1); right to a jury trial, MCL 330.1617(1); MSA 14.800(617)(1); and an extensive report assessing the persons mental, physical, social, and educational condition, and adaptive skills, MCL 330.1612 (1); MSA 14.800(612)(1). There also is the right to an independent evaluation at public expense if the individual is indigent, MCL 330.1617(6); MSA 14.800(617)(6).

These due process rights also should be afforded a parent with an alleged developmental disability before her fundamental right to raise her child is denied. Although here the surrogate decision maker would be appointed for Allison and not Ms. Bittenbender, the effect of the loss of her fundamental right to raise Allison is the same.

CONTINUING NOTICE AND THE OPPORTUNITY TO BE HEARD

A wide variety of disabilities can affect a person's decision making capacity. Some mental illnesses may be cyclical; some disabilities can be improved or cured, such as closed head injuries; and the decision-making capacities of individuals with developmental disabilities often are improved through education and experience. Thus, the capacity to make a decision as important as life support withdrawal requires that a parent be given notice and an opportunity to be heard, even after an incapacity has been determined.

Guardianship laws under Chapter Six of the Mental Health Code, MCL 330.1600 *et. seq.*; MSA 14.800(600) *et. seq.*, and the Estates and Protected Individual Code, MCL 700.1101 *et. seq.*; MSA 27.11101, *et. seq,,* allow persons to ask that their guardians' powers be terminated or modified.

> A guardian for an individual with a developmental disability . . . may be discharged, or have his or her duties modified, when the individual's capacity to perform the tasks necessary for the care of his or her person . . . have changed so as to warrant modification or discharge.

MCL 330.1637; MSA 14.800(637). (See also MCL 700.5310; MSA 27.15310.)

Both statutes recognize that guardianship "shall be designed to encourage the development of maximum self-reliance and independence in the individual." MCL 330.1602(1); MSA 14.800(602)(1) and MCL 700.5306(2); MSA 27.15306(2).

These statutes recognize that individuals with disabilities often are capable of becoming more independent and self-determined and thus allow for repeated opportunities to review the need for surrogate decision makers. The same opportunity should be given parents who have been deemed incompetent to make important decisions about their children.

ISSUE III. SURROGATE DECISION MAKERS IN LIFE SUPPORT CASES SHOULD EXERCISE THE "BEST INTERESTS" STANDARDS; BE HELD TO THE "CLEAR AND CONVINCING EVIDENCE" STANDARD; AND SHOULD NOT BE ALLOWED TO CONSENT TO THE WITHDRAWAL OF LIFE SUPPORTS IF THE SUBJECT IS NEITHER IN A PERSISTENT VEGETATIVE STATE NOR TERMINALLY ILL.[28]

THE "BEST INTERESTS" STANDARD

In general, the judicial standards to which courts turn when faced with the petition to discontinue life support for a mentally incompetent patient are the "substituted judgment" standard and the "best interests" standard. Through the substituted judgment standard, the surrogate attempts to ascertain, with as much specificity as possible, the decision the incompetent patient would make if he were competent to do so. *Martin, supra*, 450 Mich at 220-221. The best interest standard is an objective analysis under which the benefits and burdens to the patient of treatment are assessed by the surrogate in conjunction with any statements made by the patient if such statement are available, *Id*, at 219.

Courts considering treatment rights of persons with disabilities began their analysis by looking to the Due Process Clause of the Fourteenth Amendment. In the seminal *Cruzan, supra* case, the United States Supreme Court held that a competent person has a liberty interest under the Due Process Clause in refusing unwanted medical treatment. Although the court would allow surrogates to decide to refuse treatment on behalf of previously competent persons, Missouri law

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[28] This argument addresses the issues raised in Cluster III, A. See Exhibit #1.

upheld in *Cruzan* required clear and convincing evidence of prior wishes. Further, the court did not specifically extend the right to refuse unwanted treatment to persons who never were competent.

Theoretically, both competent and incompetent adults have a right to refuse medical treatment. The incompetent adult differs from a competent one in that he or she is unable to articulate a personal viewpoint about the continued provision of treatment, *Rosebush, supra*. The treatment decisions made on the incompetent adult's behalf should either express what the individual would choose if he or she were able to articulate a viewpoint, or advance that individual's best interests. "[If] such preference was never expressed or is otherwise unknown, the surrogate should make a decision based on the best interests of the patient."*Id.*, at 683.[29] In cases involving an incompetent adult who once was competent, where there is evidence of the individual's wishes regarding continued treatment, a court typically will apply a "substituted judgment" standard to the decision making process and will act in accordance with this evidence. See *Brophy v New England Sinai Hosp.*, 497 NE2d 626 (Mass. 1986). A court's application of the substituted judgment standard is regarded as inappropriate in cases in which an individual once was competent but no reliable evidence exists concerning his or her viewpoint about receiving life-sustaining treatment and in cases in which the individual has been incompetent throughout his or her life and has never had the ability to assert self-determination and privacy rights. See *Cruzan, supra*.

An incompetent adult who has never been competent is no different from a child under the *parens patriae* analysis. Both presently are unable to and have never been able to formulate and articulate a personal viewpoint about life-sustaining treatment and both are unable to protect

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[29] See also Rebecca Dresser, *Life, Death and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law*, 28 ARIZ. L. REV. 373, 399 (1986).

themselves from a potentially abusive procedure. In cases involving incompetent adults who have never been competent and in cases involving children, the court typically will apply the "best interests" standard to the treatment decision. See *In re C.A., supra*; *Custody of a Minor*, 379 NE2d 1053 (Mass. 1978); *In re L.H.R.*, 253 Ga 439; 321 SE2d 716 (Ga, 1984); *In re K.I., B.I., and D.M., supra*; *Rosebush, supra*. But see *In re Guardianship of Barry,* 445 So. 2d 365 (Fl Ct App, 1984) (using the substituted judgment standard for a 10 month old while noting "the court must be guided primarily by the judgment of the parents.")

The best interests standard recognizes the responsibility of the state, when intervening on behalf of a child, to act in its role as *parens patriae* to behave as a responsible, loving parent would behave.[30] While the substituted judgment standard occasionally has been applied to cases involving children, most scholars agree that because it is not possible to ascertain the child's wishes, courts should not apply a substituted judgment standard. *Martin, supra*, at 222.[31]

In a traditional child neglect proceeding, the juvenile court judge hears evidence describing the care the parents are providing to their child. If the court finds that the child's parents are not providing the necessary care for the child's health and well-being, the court will declare the child a neglected minor. In so finding, the court also must decide whether to make the child a ward of the court and appoint a guardian for the child is in the child's best interests.

In a proceeding considering whether a child's medical condition necessitates the provision of medical treatment over parental objections, the application of the best interest standard itself is

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[30] See Daniel B. Griffith, *The Best Interests Standard: A Comparison of the State's Parens Patriae Authority and Judicial Oversight in Best Interests Determinations for Children and Incompetent Patients,* 7 ISSUES IN L. & MED. 283, 332 (1991).

[31] See Joseph Goldstein et al.,*Before the Best Interests of the Child,* 92-93 (1979).

central to a finding of neglect. Thus, a juvenile court will base its finding that a child is a neglected minor and that a guardian should be appointed to consent to the medical treatment upon the court's determination that the treatment is in the child's best interests. As such, the application of the best interests standard to these treatment decisions differs from its application in more traditional child neglect proceedings. The analysis and standards the juvenile court applies closely resemble the analysis and standards courts apply in cases involving the continued provision of medical care to incompetent adults. A court's characterization and analysis of the standard should be of importance in its decision.

In *In re C.A.*, *supra*, a case similar Allison's, the Illinois Court of Appeals applied the "best interests" standard to the medical needs of an infant born with life threatening complications. C.A. was born several weeks prematurely, suffered from severe cocaine withdrawal, and had a myriad of complications that resulted in her being placed on an apnea cardiac monitor and ventilator. She also had a large amount of HIV in her blood. Because of her condition and the inability of her 19-year-old parents to care for her, the Illinois Department of Children and Family Services (DCFS) filed a petition for adjudication of wardship and a supplemental petition for instructions and for authority to consent to the entry of a "do not resuscitate" (DNR) order on C.A.'s medical charts. The petition alleged that C.A.'s medical condition had deteriorated and that the hospital had obtained from C.A.'s parents a letter stating their desire that their daughter receive treatment to alleviate her pain or improve her life, but not to resuscitate her if she stopped breathing or if her heart stopped. After a hearing, the juvenile court granted the petition and entered an order finding it to be "in the best interest of the minor" for the DCFS "to act in accordance with the recommendations of the treating physicians" of the patient. That order was stayed pending the appeal.

The Illinois appellate court in *C.A.* rejected the argument that the trial court was bound to apply the substituted judgment test "when almost by definition an infant has no articulable judgment to be substituted." *Id.*, at 1181. The *C.A.* court further stated:

> ... [T]he substituted judgment test is to be applied in the case of once-competent adult patients whose desire can be determined; it honors the patient's right to choose, not someone else's decision that it would be in the best interests of the patient to continue to receive life-sustaining treatments. . . . [It] is of limited relevance in the case of immature minors. If anyone's judgment is being substituted it is that of the parents or some other person with a close interest in the child's welfare. ... The Health Care Surrogate Act expressly recognizes that the best interests standard, rather than substituted judgment, applies in the case of incompetents, including minors, whose consent or desire cannot be discerned. [Statutory citation omitted].

Id.[32]

More recently, in *In Re K.I., B.I., and D.M., supra*, the court stated:

> To attempt to apply the substituted judgment test in this case ... where K.I., a child born in June 1997, has never been healthy; has issued no oral or written directives as to medical matters or formed any opinions about anything, let alone a value system; not only would be impossible, but also would violate the spirit of the substituted judgment standard, the purpose of which is to implement the wishes of the incompetent individual. Consequently, we hold, consistent with the trial court's memorandum opinion, that "in cases involving minor respondents who have lacked, and will forever lack, the ability to express a preference regarding their course of medical treatment," ... the best interests of the child standard shall be applied to determine whether to issue a DNR."

Id., at 456, 457.

The use of the best interests standard has been criticized because: (1) healthy individuals, who may undervalue the worth to a debilitated person of his existence, may misapply or improperly weigh the relevant factors and (2) society has not reached a consensus about the elements of quality of life, in applying the standard, different individuals will reach different conclusions about the same

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[32] See *In re L.H.R., supra*, recognizing that substituted judgment test is inapplicable to cases involving infants.

situation. This criticism seems misplaced. The pure form of the best interests standard is patient-centered. As such, its application should guide others to the decision that will confer the greatest net benefit to the patient. Dresser, *supra*, at 387-89. While the standard is subject to the biases of the persons who apply it, this holds true of any standard applied to treatment decisions in which the patient cannot communicate his or her wishes to others. Best interests is the standard commonly used not only in the juvenile court, but also in other judicial proceedings involving children. The best interests standard guides child custody disputes, MCL 722.23; guardianship decisions involving children, MCL700.5101; MSA 27.15101; and cases involving the termination of parental rights, MCL 712A.2d; MSA 27.3178(598.2(d).

The case law is clear that, in the case of terminating life support on an infant with disabilities such as Allison Bittenbender, the standard for decision making is a consideration of the best interest of the child, *Rosebush, supra*; *In re K.I., B.I., and D.M., supra.*

The *Rosebush* Court, quoting from *In re Guardianship of Grant, supra*,, offered the following guidelines in determining what is in the best interests of an incompetent child:

> There will be many situations where it cannot be ascertained what choice the patient would make if competent. In such cases, the guardian must make a good-faith determination of whether the withholding of life sustaining treatment would serve the incompetent's best interest. The following is a nonexclusive list of the factors which should be considered in making this determination:
>
> [E]vidence about the patient's present level of physical, sensory, emotional, and cognitive functioning; the degree of physical pain resulting from the medical condition, treatment, and termination of treatment, respectively; the degree of humiliation, dependence, and loss of dignity probably resulting from the condition and treatment; the life expectancy and prognosis for recovery with and without treatment; the various treatment options; and the risks, side effects, and benefits of each of those options. (Other citations omitted).

Rosebush, supra, at 689-690.

THE CLEAR AND CONVINCING EVIDENCE STANDARD

The *Cruzan* Court observed, the magnitude of the issue requires a high standard of proof:

> [N]ot only does the standard of proof reflect the importance of a particular adjudication, it also serves as "a societal judgment about how the risk of error should be distributed between the litigants." [Citation omitted.]

Cruzan, supra at 497 US 283.

The "clear and convincing evidence" standard is the only acceptable standard for petitions which, if successful, result in the loss of the subject's life. The Michigan Supreme Court, in *Martin, supra,* defined "clear and convincing evidence" as that evidence which:

> [P]roduces in the mind of the trier of fact a firm belief or conviction as to the truth of the allegations sought to be established, evidence so clear, direct and weighty and convincing as to enable [the factfinder] to come to a clear conviction, without hesitancy, of the truth of the precise facts in issue. . . . Evidence may be uncontroverted, and yet not be "clear and convincing." . . . Conversely, evidence may be "clear and convincing" despite the fact that it has been contradicted. [Citation omitted.]

Id, at 450 Mich 227.

The above "clear and convincing evidence" standard of proof is ideal to evaluate the evidence in this case. Other states have adopted the standard in assessing cases involving the withdrawal of a child's life support equipment. See *In re Barry, supra.*

The *K.I., B.I., and D.M.* Court used the same standard to decide whether to allow a Do Not Resuscitate (DNR) order for a comatose infant, holding that "the clear and convincing evidence standard is necessary when dealing with issues having 'far-reaching effects on individuals,' or where the consequences of a court's decision will be severe". *Id,* at 463.

Certainly, the decision to withdraw ventilator support that was keeping Allison Bittenbender alive was one that would impose "severe consequences" on her. Her treating physician, Dr. Virginia

Delaney Black, testified that it was likely that, if the ventilator were removed, Allison would die in a "matter of days to hours" (Tr. P.15). (In fact, Allison did die within two to three hours after the ventilator was removed on February 19, 1999.) Therefore, it was the responsibility of the trial court to ensure that there was clear and convincing evidence that it was in Allison's best interests to be removed from the ventilator before issuing the February 18, 1999 Report and Recommendation authorizing the hospital to take Allison off life support equipment.

The record does not support a clear and convincing finding that it was in Allison's best interests to be taken off the ventilator that was maintaining her life. Dr. Virginia Delaney Black testified in the February 17, 1999 hearing by phone. She testified that she was Allison treating physician. She never was qualified as any type of medical expert, and her credentials were not disclosed. Indeed, she later testified to her lack of experience in treating patients who presented conditions similar to Allison's.

> "Q Have you treated many babies with these same problems before?
>
> A Uh, in terms of the exact problems, no, but I have been a neonatologist for over twenty years." (Tr. At 13)

Dr. Delaney Black testified at length to Allison's heart abnormalities. She also described Allison's collapsed left lung due to her enlarged heart, which required the use of the ventilator to help her breathe. (Tr. At 6-7) Her references to other problems were cursory and inconclusive. She indicated that there was a "potential" for life threatening abnormality of the bowel, and that the bowel **may** not be normally developed, but admitted that no tests had been conducted on Allison's bowel because of the current drug and ventilator treatment (emphasis added). (Tr. At 8) She testified that Allison had severe brain abnormalities that were not then life threatening. Dr. Delaney

Black also testified that Allison would need an evaluation of her GI tract if it was decided to feed her, but did not testify to any current diagnosis of GI abnormalities or problems. (Tr. At 10)

In the face of this somewhat inconclusive testimony, Dr. Delaney Black testified that she believed it was in Allison best interest to be taken off the ventilator. When asked if Allison could be treated, Dr. Delaney Black supplied the following opinion:

> A The only treatment that we have that - would be a heart transplant and this child would not be a candidate for the heart transplant because of the other multiple malformations. I also neglected to tell you that she has dislocated hips.
>
> THE COURT: And what's the significance of that?
>
> DR. BLACK: Uh, just -- it means that in order to walk or to ---if she was physically able to, if her mental capacity were significant enough to permit her to walk, she would need casting and probably some -- potentially some surgery for that. So we are talking about a child with multiple problems. (Tr. At 12)

Dr. Delaney Black's conclusion that Allison was not a heart transplant candidate because of "multiple malformations" is not even supported by her own testimony. She spoke of Allison's **potential** bowel and GI tract problems, but she could not say that they existed. She cited dislocated hips, but gave no testimony as to why that condition made her inappropriate for a heart transplant. Her testimony did not tell what, if any, complications and/or prohibitions one collapsed lung had on a possible heart transplant. She acknowledged that Allison's brain abnormalities were not life threatening, but did not say whether or how they affected her heart transplant candidacy.

Indeed, Dr. Delaney Black's testimony as to whether Allison's "mental capacity were significant enough to permit her to walk" (Tr. at 12) appears prejudicial and discriminatory, and ignores the basic tenet that disability is a natural part of the human condition. Such considerations should not form the basis for such important decisions as termination of life support.

Dr. Delaney Black's testimony came nowhere near meeting the clear and convincing evidence requirement that it was in Allison's best interest to be removed from life support. Her testimony is rife with conclusions and hypotheticals without any medical explanation beyond vague reference to Allison's "multiple malformations." She was not qualified as an expert at the February 17, 1999 hearing, nor did the Court evidently accord her any status as an expert. There is no corroborating medical testimony.

Infant life support cases considering the clear and convincing evidentiary standard have required significantly more than was provided here by Dr. Delaney Black. The Georgia Supreme Court was explicit in what level of evidence it required before it would sanction the termination of life support:

> We conclude that the right to refuse treatment or indeed to terminate treatment may be exercised by the parents or legal guardian of the infant after diagnosis that the infant is terminally ill with no hope of recovery and that the infant exists in a chronic vegetative state with no reasonable possibility of attaining cognitive function. The above diagnosis and prognosis must be made by the attending physician. Two physicians with no interest in the outcome must concur in the diagnosis and prognosis.

In re L.H.R, supra.[33]

The decision of whether to remove Allison's ventilator should have been made using the best interest standard. The trial court's determination that the removal was in Allison's best interest was not supported by clear and convincing evidence on the record, and the court therefore erred in issuing its Report and Recommendation allowing the removal of Allison's ventilator.

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[33] See also *In re C.A., supra*, (the court qualified the attending physician as an expert, took her testimony, and then adjourned the hearing until a second opinion could be obtained from another physician the Court qualified as an expert); *In re K.I., B.I. and D.M., supra* (testimony was taken from a number of experts in meeting the clear and convincing standard, including experts in pediatric critical care, bioethics, and ethics); and *In re Guardianship of Barry, supra,* (diagnosis must be made by at least two physicians).

PERSISTENT VEGETATIVE STATE AND TERMINAL ILLNESS

The *Martin, supra* Court left open the question of how to approach the case where a person subject to a petition to withdraw life support has "never been competent, ... [is] existing in a persistent vegetative state, ... experiencing great pain or ... terminally ill." *Id.*, at 223, n 15.

Here, as argued immediately above, the evidence on Allison's condition at the time of the petition neither clearly nor convincingly established that she was terminally ill, nor that she was not aware of her surroundings. But she is an infant, and had never been competent to make her own decisions.

In all U.S. jurisdictions, competent adults have the option of establishing advance directives to guide health care providers in honoring end of life decisions. Meisel, *supra*, VII p. 120, 211-212. The applicable Michigan statute is the Uniform Durable Power of Attorney Act. MCL 700.5501-5512; MSA 27.15501-15513. Adults may create a written directives advising of their decisions for their own life-sustaining treatment. In Michigan, there is no express limitation in the law as to when life-sustaining treatment may be removed; any limitations on removal of treatment are established by the written document. The patient advocate may only direct withdrawal of life-sustaining treatment in those situations expressly provided for in the patient's durable power of attorney document.

In contrast to Michigan's reliance on a patient to explicitly set any limitations on withdrawal of treatment, provisions in 42 other states place diagnostic limitations on when an advance directive becomes effective or when its directives may be executed.[34] Meisel, *supra*, describes the array of

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[34] See MPAS Exhibit 5, attached, a chart which analyzes the medical [terminal illness and/or persistent vegetative state] and diagnostic [number and class of physicians] conditions which much exist prior to the directive becoming effective and authorizing the designated person to authorize the removal of life

required conditions among the different states:

> [M]ost statutes use one or more of several terms- *terminal condition*, *permanent unconsciousness*, *qualified patient*, and *life-sustaining procedure*- to describe the category of persons whose living wills are effective and the circumstances under which they are enforceable. That is, under most statutes a living will becomes effective only if the patient is terminally ill or permanently unconscious; some statutes use the phrase *qualified patient* to refer to such a person.

Id., at VII p.95.

Currently, 25 of those 42 states which require a diagnosis of a terminal condition, permanent vegetative state, and/or permanent unconsciousness *also* require that the diagnosis be confirmed by a physician other than the attending physician.[35]

People who have never achieved competence to establish advance directives, due to age or disability, are not able to assume the obligations of Michigan's patient advocate law and cannot avail themselves of the opportunity to explicitly state that life-sustaining procedures should be undertaken unless they are terminally ill or in a persistent vegetative state. The state has an obligation to provide those protections for persons who cannot utilize the existing statute, which is only applicable to patients who were once competent and have established a durable power of attorney. No life-sustaining treatment should be withdrawn from an incompetent patient unless that individual has a terminal condition or is in a persistent vegetative state that is verified by at least one physician other than the attending physician *and* that physician has personally examined the patient.

In states which have those limitations written into existing statutes, there is merely a small step to take in making those conditions applicable to patients who were never competent. As Meisel

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support systems.

[35] See MPAS Exhibit 6, attached, which cites the state statutes and sets forth the statutory definitions used by the various states to define medical and diagnostic terms and conditions.

notes, "... [T]he statutory requirement that the patient be in a terminal condition or permanently unconscious before the advance directive becomes effective could be applied to patients without advance directives to prohibit the forgoing of life-sustaining treatment unless the nondeclarant were terminally ill or permanently unconscious as well." *Id.*, VII p.31. In Michigan, the definitive establishment of those limitations is merely a small step from current public policy.

Likewise, investigating the case law of the several states,[36] no case law has sanctioned the removal of life support systems from a person who is neither terminally ill nor in a persistent vegetative state absent clear and convincing evidence of that person's previously expressed desire.

The situation here, however, is different in that Allison was an infant, unable to express her desires or choices. How, as a matter of policy, is the court to decide a standard here?

The answer seems clear when the Act and the efforts of the several States are considered. The policy has evolved that terminal illness or the existence of a persistent vegetative state are thresholds over which the balancing referred to in Issue I begins. Most states manifest the State's interest in preserving life *for competent adults* by limiting or barring the effectiveness of their end of life declarations until they either are terminally ill or in a persistent vegetative state. Half the stats not only require that condition, but require a confirming diagnosis from a physician who is not treating the patient. Can any lower standard abide here, where Michigan's interest in preserving life is buttressed by its equally compelling *parens patriae* interest in protecting those who cannot protect themselves?

Rosebush, supra, would leave the decision to the family. That does not resolve the issue if, unlike Joelle Rosebush, the child is not terminally ill or in a persistent vegetative state. The risk of

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[36] Exhibit #7 sets out the current state of case law in those states having reported cases.

well-intentioned, but erroneous judgments on quality of life cannot be overemphasized. The danger to children with disabilities is great if this Court permits surrogate decision makers to withhold or withdraw life sustaining medical treatment or equipment from children who, while not being terminally ill or in a persistent vegetative state, still have significant and challenging physical or mental disabilities.

This Court should adopt the "best interest" standard; require that those best interests be clearly and convincingly proven; and hold as a matter of law that the best interest standard cannot be clearly and convincing proved unless the petition subject is either in a persistent vegetative state or terminally ill.

ISSUE IV: PHYSICIANS AND HOSPITAL ETHICS COMMITTEES SHOULD NOT BE PERMITTED TO UNILATERALLY EMPLOY A THEORY OF FUTILE CARE TO DISCONTINUE LIFE-SUSTAINING TREATMENT BECAUSE THE FUTILE CARE THEORY IS LIMITED BY SUBJECTIVE FACTORS THAT MAY INFLUENCE ASSESSMENT OF A PATIENT'S PROGNOSIS.[37]

The classic right-to-die cases that have earned judicial and media attention for the past twenty-five years have arisen when patients, family members, and other surrogate decision-makers sought to withdraw life-sustaining treatment. Hospitals and physicians turned to judicial review as a means of protecting their own interests regardless of the moral stance taken by medical providers. There is now a widely recognized right to the withdrawal of life-sustaining treatment for competent patients based on a Constitutional right to privacy and the common law principle of informed consent. *Cruzan, supra; Martin, supra; Rosebush, supra.* Incompetent patients do not lose this right, although it must be exercised on their behalf by a surrogate decision maker. *Id.*

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[37] This issue addresses the questions raised in Cluster III, D, E. See Exhibit #1.

The futility debate asks the reverse question - what is the right of a patient, whether competent or incompetent, to receive life-sustaining treatment that medical professionals deem futile? "The fundamental legal question in the futility debate is whether the right of self-determination encompasses a 'positive' legal right to compel the provision of treatment or whether it is limited to the long-standing 'negative' right to be free from unwanted interferences with bodily integrity." Meisel, *supra* Vol. 2, p.530. There is no recognized Constitutional right to health care which would extend to the provision of futile care. *DeShaney v. Winnebago County Dept. of Social Services*, 489 U.S. 189, 193 (1989). Courts have only begun to address common law rights to receive futile medical care. Meisel, *supra*, p. 530. Legislation will be difficult to achieve in this area because of the contentious debate about the state's interest in life and the competing interest of health care costs. *Id.*

The case law in this area is currently undeveloped. The Fourth Circuit has addressed the issue of futile care in the context of an infant who was born with only a brain stem but no cerebral cortex, a condition known as anencephaly. *In re Baby K*, 16 F.3d 590 (4th Cir. 1994), *cert. denied* 513 U.S. 825 (1994). The child needed periodic ventilator treatment due to recurring episodes of respiratory distress. The hospital sought declaratory relief and immunity from liability if the baby was refused ventilator treatment when brought to the emergency room from her nursing home. The mother strongly resisted any denial of emergency treatment to her baby.

The hospital argued that it was futile to keep alive an anencephalic infant. The trial court rejected this argument and stated that it was neither "futile" nor "inhumane" to relieve a person's acute respiratory distress. *In re Baby K*, 832 F.Supp. 1022, 1027 (E.D. Va. 1993). The Fourth Circuit upheld the trial court's ruling that the hospital would be liable under the Emergency Medical

Treatment and Active Labor Act (EMTALA) if the child were denied treatment. *In re Baby K*, 16 F.3d at 592.

One state trial court that has addressed the issue of withdrawal of care against a surrogate decision-maker's expressed desires found that Constitutional liberty interests and a common law right of self-determination were implicated. *Rideout v. Hershey Medical Center*, 30 Pa. D. & C.4th 57 (1995). A two-year child with a brain tumor was disconnected from a ventilator based on a decision made by a hospital's ethics committee and against the wishes of her parents. *Id.* "Accordingly, under both federal and state constitutional law, it appears, based upon the facts alleged, that Brianne's particularized interest in her own life was infringed upon when the hospital decided, unilaterally...to discontinue her life-support." *Id.* at 78.

The medical community has advanced three scenarios in which it is inappropriate to render treatment beyond palliative care: (1) The patient is terminally ill and death is inevitable; (2) the patient is unconscious and there is no reasonable expectation that cognition will return; or (3) the patient is brain dead. Claire C. Obade, *Patient Care Decision-Making: A Legal Guide for Providers*, (St. Paul, MN: West Group, 1999), p.10-3. While these guidelines may offer assistance to physicians in determining the optimal level of care, that does not give physicians license to make unilateral decisions without input from family members or other surrogate decision makers. Decisions about medical care that ultimately decide if a person will live or die should always be made collectively. *See* Spielman, B., "Collective Decisions About Medical Futility," 22 J. Law, Med., and Ethics 152 (1994).

"Many physicians and other providers who have not been involved in litigating these types of cases are unaware of the degree to which a prognosis should be confirmed before treatment is withheld or withdrawn." Obade, *supra,* p. 10-3. The U.S. Commission on Civil Rights has recognized the problem of bias in determining a prognosis for a gravely ill patient, "Physicians may have a propensity for negative prognosis at least in part because they tend to see children with disabilities at the time that the children are in the hospital and their conditions are at their worst." U.S. Commission on Civil Rights, *Medical Discrimination Against Children with Disabilities*, p. 5 (1989).

"Futility is a subjective and nebulous concept which, except in the strictest physiological sense, incorporates value judgments." *Causey v. St. Francis Medical Center*, 719 So 2d 1072, 1075 (La Ct App, 1998) (affirming that plaintiffs have a medical malpractice claim for the death of a 31 year old family member who was disconnected from life support against the family's expressed objections). One concept of futility includes within its domain medical care that may have a physiological effect but would not improve the patient's quality of life. "At its core, what the dispute in futility cases is about is quality of life - who decides what it is and when it justifies the administration or forgoing of life-sustaining medical treatment." Meisel, *supra*, p. 535.

The theory of "futile care" cannot be used to permit life support decisions to remain the province of the treating medical professionals. Here, applying the "futile care" doctrine resulted in the withdrawal of Allison's life support equipment even though she was neither terminally ill nor in a persistent vegetative state. The theory of futile care cannot be properly applied to the termination of Allison's life support. The record below does not support a conclusion that any treatment of Allison would be futile. As noted previously, Dr. Virginia Delaney Black's testimony is conclusory and without any corroboration or independent confirmation. In addition, her testimony reveals a projection of her own view of the value of Allison Bittenbender's life that is an inappropriate factor to be considered in deciding whether life support should be removed:

"Q Why do you feel it's more ---it's in the child's best interest to remove this life support at this time?

A Because we have no medical treatment to offer this ---this child in the long run and I think what care is futile to ask an infant to suffer on a ventilator with a tube in their throat, unable to be fed with I.V.s and not being able to easily be held or **provided with the kinds of life that one would want**, that is not a humane decision." (emphasis added) Tr. At 15-16.

Dr. Delaney Black clearly imposed her own perception of the quality of life in rendering the opinion that any care that could be provided to Allison would be futile. As has already been noted, there is no clear and convincing evidence that the termination life support was in Allison's best interest. If the Courts have held that a decision to terminate life support must be proven by clear and convincing evidence, the concomitant decision that any further care would be futile must also necessarily meet that same evidentiary standard. Since the record below does not conclusively explain why Allison Bittenbender's "multiple malformations" would preclude her from a heart transplant and there is no corroborating or independent medical testimony, there has been no adequate showing that any treatment that might be available to Allison, or leaving her on life support until a determination could be made, would be "futile". Dr. Delaney Black's testimony that Allison was conscious, had never been in a coma, and had movement and brain functioning further put her outside the guidelines that the medical community has put forth as appropriate situations where only palliative care may be provided. (Tr. at 16) Obade, *supra.*

Dr. Delaney Black's characterization of the quality of Allison Bittenbender's life is not an appropriate basis to make a decision cloaked as a "medical opinion." The Department of Health and Human Services, the federal agency responsible to implement the Child Abuse Amendments of 1984, has stated "the law [does] not permit life and death treatment decisions to be made on the basis of subjective opinions regarding the future 'quality of life' of a retarded or disabled person." (Child Abuse and Neglect Prevention and Treatment Program, 50 Fed.14878,14879 (1985); see also 45 CFR 1340, App. Interpretive Guidelines 9).

In 1984, nine major disability and medical associations adopted a position statement entitled *Principles of Treatment of Disabled Infants* that also rejected using a 'quality of life' determination as a criterion:

> Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care.

Joint Policy Statement: Principles Of Treatment of Disable Infants, 73 Pediatrics 559,559 (1984).[38]

It is clear from the testimony of Dr. Delaney Black that her own subjective opinion of the quality of Allison Bittenbender's life was a significant factor in her determination that any care for Allison would be futile. Such consideration is prohibited under federal law in making life and death treatment decisions. 45 CFR 1340.

For these reasons, this case does not allow application of the theory of futile care.

SUMMARY AND RELIEF SOUGHT

MPAS has addressed this Court's questions appearing in Cluster I, B; Cluster II, B; and Cluster III, A, B, C, D and E. MPAS appreciates the complex decision resting before this Court.

Michigan's laws, policy and jurisprudential history strongly favor the preservation of life,

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[38] The signing groups included the Association for Retarded Citizens, the National Down's Syndrome Congress, the American Coalition of Citizens with Disabilities, Inc., the Association for Persons with Severe Handicaps, the American Association on Mental Deficiency, the American Association of University Affiliated Programs for Persons with Developmental Disabilities, the Spina Bifida Association of America, the National Association of Children's Hospitals and Related Institutions, Inc., and the American Academy of Pediatrics.

particularly the lives of those whose life support decisions must be made by surrogate decision makers. Interested parties, including the FIA, should have court access to raise concerns about an infant's care and treatment.

Parents who are alleged to be incompetent to make decisions for their children are entitled to the full panoply of due process rights afforded by the 14th Amendment and by Michigan statutes before they are barred from making decisions for their children and from participating in court actions affecting their children's very lives. Kitty Bittenbender's fundamental liberty interests in parenting Allison were arbitrarily and cruelly extinguished without consideration for her or for Allison.

Michigan courts considering the removal of an infant's or child's life support should use the "best interest" standard and require clear and convincing evidence that the proposed removal is in the subject's best interest. As a matter of law, it can never be in a child's best interests to have life support removed if the child is neither terminally ill nor in a persistent vegetative state.

The scope of a surrogate's authority to consent to medical "treatment" includes the ability to consent to the withholding or withdrawal of life support equipment. A medical professional's opinion that medical care would be futile cannot be allowed to supersede the wishes of a patient or the patient's surrogate decision maker that life support equipment should be used or maintained. Disability is a natural part of the human condition, and the concept of "futile care" allows the elevation of "quality of life" considerations that frequently are weighed against an infant or child who has serious, but non-terminal medical conditions or disabilities. Here, Allison Bittenbender was a victim of a physician's erroneous determination that the quality of her life was more important than her right to life itself. The evidence presented here neither clearly nor convincingly established that

Allison was in a persistent vegetative state or terminally ill. The evidence also did not clearly and convincingly establish that it was in her best interests to remove her ventilator and to allow her to die.

This Court must act to remedy the immediate peril all infants, children and adults who never have been competent find themselves in. Michigan's interest is in preserving *all* life. The lower court must be reversed. This Court must declare the standards and definitions to be used until the Michigan Legislature acts.

For all these reasons, MPAS asks this Court to reverse the decision of the Wayne County Circuit Court, Family Division.

Respectfully submitted,

MICHIGAN PROTECTION AND
ADVOCACY SERVICE, INC.

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Dated: June 26, 2001

MPAS EXHIBIT #1

Question Cluster I – Parental or Familial Rights:

A. What rights do a putative parent or family members of an incompetent minor child have to participate in a judicial proceeding seeking withdrawal of the child's life support? In answering this question, consider whether the doctrine of judicial nonintervention, see *In re Rosebush*, 195 Mich App 675, 687; 491 NW2d 633 (1992), applies to a medical treatment decision by a putative parent or family member and whether these individuals are entitled to all the procedures extended to a legal parent, such as notice and the right to an attorney.

B. Please describe the standards and procedures that must be used once someone alleges that a parent is mentally incompetent to make a medical decision for the parent's incompetent minor child to ensure that the parent is able to participate in the medical decision to the fullest extent possible. Consider:

- Whether parental incompetency may be established by allegation alone or must be proven by a preponderance or by clear and convincing evidence;
- If there must be a designated competency hearing with external evidence of parental incompetency, such as expert testimony, or whether a family court may determine competency based on informal evidence, such as firsthand observation at a hearing held for another purpose;
- Whether a parent who is proven to be incompetent is nevertheless entitled to notice and an opportunity to be heard at all proceedings following the incompetency determination;
- If a family court must appoint a legal guardian or attorney for a parent as soon as the parent is alleged to be incompetent or after the parent is determined to be incompetent;
- Whether the family court must review the parent's mental incompetency more than once to allow a parent who regains competency to make the medical decisions at issue. For example, when a parent is incompetent because of unconsciousness, does the family court need to review whether the parent has regained competency at each hearing to allow the parent to participate in the proceedings once conscious?

C. May the Family Independence Agency petition a family court to permit or bar withdrawing life support from a minor child if there is insufficient evidence of actual abuse or neglect, as defined in MCL 712A.2; MSA 27.3178(598.2), to initiate a child protective proceeding?

D. In order to prevent judicial intervention in a case where a competent parent who is not abusive or neglectful and is willing and able to make a decision regarding life support for a minor child, must a family court hold an adjudication on the allegations of abuse and neglect in the petition initiating the child protective proceeding before the family court enters an order permitting or barring withdrawal of the child's life support?

Question Cluster II - Rights of an Incompetent Minor Patient

A. Does a child in a protective proceeding have the right to effective assistance of counsel? If so:

- Do the standards developed for the right to effective counsel in criminal cases define effective representation for a child in a protective proceeding or do other legal standards apply?

- What are the minimum standards for representing the child?

- Do the same or different standards apply to a child's appointed counsel and an attorney who substitutes for the child's original counsel on a temporary basis (e.g., emergency house counsel)?

- Must a substitute attorney determine and continue the original appointed counsel's position on withdrawal of life support?

- Is reversal of the outcome of the proceedings in which a child was denied the right to effective assistance of counsel the appropriate remedy, or is another remedy more appropriate?

B. Please describe the minimum procedural protections that a family court must offer to a minor child in a case affecting continuation or withdrawal of life support. Consider the extent to which the family court must ensure that:

- The child's parents are notified of and offered an opportunity to participate in proceedings concerning the child;

- A guardian ad litem is appointed for the child;

- A lawyer is appointed for the child;

- There is a second medical opinion confirming the child's diagnosis and prognosis;

- At least one party to the proceedings argues against withdrawing life support or identifies what such an argument would be;

- The hearing referee and/or a judge makes a substantive inquiry on the record concerning procedural issues such as notice to parents, the identity of the attorney appointed to represent the child if substitute counsel appears at a hearing, and the efforts the guardian ad litem and/or lawyer for the child have made to monitor the child's condition, etc.;

- If a hearing referee holds one or more hearings in the case, there is substantive judicial review of the hearing referee's findings and recommendations.

Question Cluster III – General

A. In the case of an incompetent (and never competent) infant and hypothetically incompetent or absent parents, who stands as surrogate for the infant?

- Who makes, or should make, the determination to appoint the surrogate?
- What is the authority of the surrogate?
- What are the duties of the surrogate?
- Under what standards should the surrogate recommend, make or acquiesce in decisions concerning the infant's care? If the standard is the substituted judgment standard, how is the surrogate to ascertain what the infant would have decided? If the standard is the best interests standard, should the fact that the infant is severely disabled be taken into account when weighing the burdens and benefits of care, the risks and the costs, the potential for pain and other factors? See *In re Rosebush, supra* at 689-690, quoting *In re Guardianship of Grant*, 109 Wash 2d 545, 567-568; 747 P2d 445 (1987), modified 757 P2d 534 (1988), citing to *In re Conroy*, 98 NJ 321, 327; 486 A2d 1209 (1985) (Handler, J. concurring in part and dissenting in part) (summarizing the best interests standard).

B. Is appellee Family Independence Agency correct when it contends the term "treatment" encompasses situations when it is appropriate not to use medical technology based on the opinion of a physician who is trained in the use of medical technology? Does *In re Rosebush, supra*, support such a contention?

C. In situations where the state, through an executive branch agency, is the party seeking to have life support withdrawn:

- How are the state's interests in (1) the protection of life, (2) the protection of innocent third parties, (3) the prevention of suicide, and (4) the maintenance of the ethical integrity of the medical profession to be advanced? See *Rosebush, supra*; *Grant, supra*; Meisel, *The Right To Die* (New York; Wiley Law Publications, 1989), pp 96-100; anno, *Judicial power to order discontinuance of life sustaining treatment*, 48 ALR 4th 67.
- How is the policy of judicial nonintervention articulated in *Rosebush, supra* at 687, to be best implemented? How is it to be determined "when the parties directly concerned disagree" about treatment? What other appropriate reasons are there for the court's involvement?
- What constraints are there, in the United States and the Michigan Constitutions, in federal and Michigan statutes and in case law upon the state's actions? If, as appellee Family Independence Agency asserts, there is no prohibition on the state's ability to seek the withdrawal of life support, can this be construed as an authorization for seeking such withdrawal?
- Assuming that the family court had subject matter jurisdiction over AMB under MCL 712.2(b)(1) or (2); MSA 27.3178(598.2)(b)(1) or (2) as a result of the allegations of neglect in the original petition, did the second petition, which sought the withdrawal of life support,

divest the court of its subject matter jurisdiction because it changed the focus of the proceedings from protecting AMB to ending her life?

D. Assuming a brief description of "futile care" to be a situation in which a patient reaches a certain stage of age, illness, injury or disability so that any further treatment other than comfort care would make no difference in the patient's prognosis, is this a case for the proper application of a theory of futile care? What are the limits of such a theory? How should the decision be made as to what treatments are futile and under what standards? Who should make such decisions?

E. Of the questions and issues set out above, which should be most appropriately addressed by the legislative branch, by the executive branch, or by the judicial branch?

Presiding Judge

STATE OF MICHIGAN COURT OF APPEALS

A true copy entered and certified by Sandra Schultz Mengel, Chief Clerk, on

APRIL 2, 2001
Date

Sandra Schultz Mengel
Chief Clerk

MPAS EXHIBIT #2

JUDGE DAVID L.
BAZELON
CENTER
FOR
MENTAL
HEALTH
LAW

Civil Rights and Human Dignity

June 22, 2001

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of this organization's support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, Inc. (MPAS) in the above captioned matter. Our organization has reviewed this brief and supports the positions taken by MPAS on the issues addressed.

The Bazelon Center for Mental Health Law is a national public interest organization founded in 1972 to advocate for the civil rights and human dignity of individuals with mental disabilities. The Center has engaged in litigation, administrative advocacy, and public education to promote self determination and equal opportunities for individuals with mental disabilities. The Center has serious concerns about the implications of the issues presented to this Court concerning the rights of parents with mental disabilities to make decisions concerning their children as well as the termination of life support for individuals with mental disabilities.

On behalf of the interests of the persons with disabilities that our organization represents, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Very truly yours,

Jennifer Mathis

Jennifer Mathis
Staff Attorney
Bazelon Center for Mental Health Law

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The Arc Michigan

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(517) 487-5426 or 1-800-292-7851
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June 22, 2002

The Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

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Docket No. 218869
LC No. 99-375617

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Please accept this letter as a statement of this organization's support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, Inc. (MPAS) in the above captioned matter. Our organization has reviewed this brief and supports the positions taken by MPAS on the issues addressed.

The Arc Michigan is our state's largest grassroots volunteer disability organization, with 12,000 members and 50 local chapter affiliates. We exist to empower local chapters of The Arc to assure that citizens with developmental disabilities and their families are valued and can participate fully in, and contribute to, the life of their chosen community. A major priority of our organization is ensuring the civil rights of our constituency, which we believe were blatantly violated in the referenced matter.

On behalf of the interests of persons with disabilities that our organization represents, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Thank you for the opportunity to communicate our thoughts.

Most sincerely,

Eric A. Richards, Executive Director
The Arc Michigan

a state organization on mental retardation and other developmental disabilities
(formerly Association for Retarded Citizens/Michigan)
affiliated nationally with The Arc

Michigan Disability Rights Coalition

With Liberty and Access For All

June 21, 2001

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

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Michigan Disability Rights Coalition is a state-wide network of individuals and organizations that advances the issues of Michigan's disability community through community capacity building, grassroots organizing, education, and advocacy. The Coalition's view of the issue in the above captioned case can be no more clearly stated than it is in the MPAS brief. "Michigan courts should strictly construe statutes and case law to protect the lives of the petition subjects." The devaluing of the lives of persons with disabilities is a constant and dangerous stereotype of our current culture. We hope that no Michigan court will use that stereotype as a legal standard.

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On behalf of the interests of the persons with disabilities that our organization represents, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Very Truly Yours,

Norman G. DeLisle, Jr.
Executive Director

NOT
DEAD
YET
The Resistance

June 22, 2001

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of this organization's support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, Inc. (MPAS) in the above captioned matter. Our organization has reviewed this brief and supports the positions taken by MPAS on the issues addressed.

Not Dead Yet is a national grassroots organization of people with disabilities formed in response to the increasing popularity of, and laws permitting, physician assisted suicide and euthanasia in the United States and around the world. Not Dead Yet's mission is to advocate against legalization of physician assisted suicide and euthanasia, and to bring a disability-rights perspective and awareness of the effects of discrimination to the legal and sociological debate around euthanasia and physician assisted suicide. Formed in 1996 in Illinois, Not Dead Yet has worked to educate, support, coordinate and lead the disability community's effort to stop the "right to die" from becoming a duty to die or a right to kill. Not Dead Yet's amicus brief, with co-amici ADAPT, filed in the U.S. Supreme Court in the case of *Vacco v. Quill*, 117 S.Ct. 2293 (1997), was among a handful, out of over 60 such briefs, cited by the high Court in its final opinion. Not Dead Yet has given invited testimony before the U.S. Congress three times, once before the U.S. Senate Judiciary Committee and twice before the Constitution Subcommittee of the U.S. House of Representatives.

On behalf of the interests of the persons with disabilities that our organization represents, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Very Truly Yours,

Diane Coleman

Diane Coleman, President

7521 Madison Street - Forest Park, IL 60130 - 708-209-1500 (V) - 708-209-1826 (TTY) - 708-209-1735 (TTY)

UCP
Understanding Disabilities
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Linda Potter
Executive Director

June 25, 2001

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of the support of United Cerebral Palsy of Michigan (UCP Michigan) of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, Inc. (MPAS) in the above-entitled matter. We have reviewed the brief and we support the positions taken by MPAS on the issues addressed.

The mission of UCP Michigan is to advance the independence, productivity and full citizenship of citizens with cerebral palsy and other disabilities. It appears that A.M.B. had disabilities from birth, and her mother either has or was treated as if she has a disability in the days following her daughter's birth. The issues in this case - about death and parenting and who makes life and death decisions and how such decisions are made – are critically important for all persons with cerebral palsy and other disabilities, and as a disability advocacy organization we support the effort to find solutions which value and protect the rights of people with disabilities and enhance their self-determination.

Thank you for the opportunity to provide our support of the MPAS brief. It is our hope that the brief and the support from other disability organizations will aid the Court as it considers the serious issues in this matter.

Sincerely,

Andrea J Sarto

Andrea Sarto
President

Linda Potter

Linda Potter
Executive Director

UCP

**United Cerebral Palsy
of Metropolitan Detroit**

23077 Greenfield, Suite 205
Southfield, MI 48075-3745
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fax 248-557-4456
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www.ucp.org

June 21, 2001

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of UCP of Metropolitan Detroit's support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, Inc. (MPAS) in the above captioned matter. Our organization has reviewed this brief and supports the positions taken by MPAS on the issues addressed.

UCP of Metropolitan Detroit's mission is to advance the independence of people with disabilities and to promote opportunities for self-determination and inclusion of people with disabilities into the community. UCP/Detroit strongly believes that irrespective of characteristics associated with disabilities, all people deserve full protection under the law.

On behalf of the interests of the persons with disabilities that UCP of Metropolitan Detroit serves, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Sincerely,

Elmer L. Cerano,
President

ELC/aa

[illegible] letter of support

AUTISM SOCIETY OF MICHIGAN

6035 Executive Drive, Suite 109 • Lansing, Michigan 48911
(517) 882-2800 • Fax (517) 882-2816 • In Michigan: (800) 223-6722
email address: miautism@aol.com • website address: autism-mi.org

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re Allison M. Bittenbender, a minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of this organizations support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, Inc. (MPAS) in the above captioned matter. Our organization has reviewed this brief and supports the positions taken by the MPAS on the issues addressed.

An excerpt from the mission statement of the Autism Society of Michigan is "to assure full participation and self-determination in every aspect of life for each individual." It is certain that Allison Bittenbender was not allowed full participation or self-determination in this part of her life.

On behalf of the interests of the persons with disabilities that our organization represents, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Sincerely,

Sally Burton-Hoyle

Sally Burton-Hoyle
Executive Director

ASM advocates that "MAKING HUMAN CONNECTIONS" in a supportive, integrated community is a right of all persons.
ASM is a United Way Agency and ASA chapter.

**Center for
Self-Determination**

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re: Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of this organization's support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Service, In.c (MPAS) in the above-captioned matter. Our organization has reviewed this brief and supports the positions taken by MPAS on the issues addressed.

The Center for Self-Determination promotes the idea that people must have full say in how their lives are lived especially when public funds are involved. When systems control funds, lives tend to diminish in quality and costs tend to increase. The Center is committed to reversing these historical tendencies, changing the rules and transferring power to those with disabilities. On the bases of good evidence and important values the Center believes that, when power and control over human lives moves responsibly from systems to the people themselves and their freely chosen allies, lives improve and better value is achieved for the dollars spent.

On behalf of the interests of the persons with disabilities that our organization represents, we hope this brief and our support of it will be helpful in the Court's deliberations on the difficult issues presented in this matter.

Sincerely,

Thomas Nerney

Thomas Nerney
Executive Director

3625 MetroPlace Mall • Wayne, MI 48184
734.722.6262 • fax 734.467.7639
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WASHTENAW
ACA

ASSOCIATION FOR COMMUNITY ADVOCACY
Advocating for People with Disabilities (formerly WARC)

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NEW Center
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Dohn Hoyle, President
Kathleen Neuman, Board Chair

Honorable William C. Whitbeck
Presiding Judge
Court of Appeals
State of Michigan

Re: In re: Allison M. Bittenbender, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

Please accept this letter as a statement of our organization's full support of the Amicus Brief on Appeal filed by Michigan Protection and Advocacy Services, Inc. on the above-captioned matter. We have read and reviewed this brief and support the positions taken on the issues addressed.

The Association for Community Advocacy, formerly the Washtenaw Association for Retarded Citizens, is a membership based, cross-disability organization some fifty-one years old. We were one of the first organizations in the state or country to advocate for persons with disabilities and their families. We are a recognized leader in disability rights throughout Michigan and the Nation. We advocate across the life span for individuals with disabilities and families to promote best practices and to facilitate change, which will permit each person to fully participate in and contribute to their community.

We are, therefore, particularly dismayed at what occurred in this matter. It is our hope that our support of this brief, on behalf of those we attempt to represent, will assist the court in its deliberations and that the results will be to forestall future occurrences of such an appalling nature.

Thank you for your consideration in this matter.

Sincerely,

Dohn Hoyle

NATIONAL LEGAL CENTER
FOR THE MEDICALLY DEPENDENT
& DISABLED, INC.

7 South 6th Street, Suite 208 ● Terre Haute, IN 47807 ● 812-238-0769 ● FAX: 812-232-0260

June 25, 2001

Honorable William C. Whitbeck
Presiding Judge Court of Appeals
State of Michigan

Re: *In re Allison M. Bittenbender*, a Minor
Docket No. 218869
LC No. 99-375617

Dear Judge Whitbeck:

The purpose of this correspondence is to inform the Court of Appeals that the National Legal Center for the Medically Dependent & Disabled, Inc., strongly supports the arguments made by amicus curiae, Michigan Protection and Advocacy Service, Inc. ("MPAS"), in the above-named case. The National Legal Center has reviewed the MPAS brief, and we endorse the legal arguments and positions represented by the MPAS.

The National Legal Center for the Medically Dependent and Disabled, Inc., was founded in 1984; it is a not-for-profit, public interest law firm providing litigation support and policy consultation on matters related to foregoing life-sustaining treatment or care, active euthanasia, and assisted suicide. The National Legal Center is opposed to withholding or withdrawing of life-sustaining treatment or care from non-competent persons, including infants, on the basis of disability or "quality of life" considerations or against the expressed wishes of such persons or their surrogates. The National Legal Center has been involved in over 100 cases concerning foregoing of medical treatment or care, including several cases in Michigan.

The National Legal Center, on behalf of its client population of persons in need of life-sustaining treatment or care, urges the Court of Appeals to carefully regard the arguments and positions adopted by the MPAS brief.

Respectfully,

Thomas J. Marzen

Thomas J. Marzen
General Counsel

MPAS EXHIBIT #3