



NEW YORK STATE TASK FORCE ON LIFE & THE LAW

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Honorable John L. Sampson
Majority Conference Leader, New York State Senate
Legislative Office Building
188 State Street, Room 409
Albany, New York 12247

Honorable Dean G. Skelos
Minority Leader, New York State Senate
Legislative Office Building
188 State Street, Room 907
Albany, New York 12247

Honorable Sheldon Silver
Speaker, New York State Assembly
Legislative Office Building
188 State Street, Room 932
Albany, New York 12248

Honorable Brian M. Kolb
Minority Leader, New York State Assembly
Legislative Office Building
188 State Street, Room 933
Albany, New York 12248

Dear Senators Sampson and Skelos, and Assembly Members Silver and Kolb:

On behalf of the New York State Task Force on Life and the Law (the “Task Force”), I am pleased to submit for your consideration, *“Recommendations Regarding the Extension of the Family Health Care Decisions Act to Include Hospice.”*

The Task Force was created by Executive Order in 1985 to develop public policy on issues arising at the interface of law, medicine, and ethics. Since then, the Task Force has issued influential reports on a variety of bioethics issues, including genetic testing, assisted reproductive technologies, allocation of ventilators in the event of a pandemic influenza outbreak, and organ donation.

The Task Force commends the Legislature on the passage of the Family Health Care Decisions Act (“FHCDA”) in March 2010, which provides New Yorkers with an invaluable tool to facilitate surrogate decision-making for health care. Prior to the FHCDA, families and close friends of patients did not have the authority to make even routine health care decisions on a patient’s behalf, and were required to satisfy an extremely high evidentiary burden when the decision concerned the withholding or withdrawing of life-sustaining treatment. The FHCDA greatly improved this situation by authorizing surrogates to make health care decisions for loved

ones in hospitals and residential health care facilities. However, it still leaves thousands of New Yorkers who receive care in other settings and who cannot speak for themselves without the benefit of a surrogate decision-maker.

The Legislature directed the Task Force to examine whether the FHCDA should be amended to apply to decisions for health care provided in settings outside of hospitals and residential health care facilities. *See* 2010 N.Y. Laws Ch. 8, § 28 (2). Over the past several months, the Task Force has deliberated over the ethical and legal issues raised by extending the FHCDA, and is prepared to make an initial recommendation that the FHCDA should be amended to provide surrogates with authority to make decisions on behalf of incapable patients for hospice care.

In order to be eligible for hospice, a patient must suffer from a terminal illness and have a life-expectancy of six months or less. These patients' conditions often affect their ability to make choices or express wishes, precisely at a time when they face many important health care decisions. Accordingly, surrogate decision-making for these vulnerable patients is crucial to ensuring that their rights and welfare are protected, and that they live the remainder of their days in dignity and with appropriate care.

As is set forth in further detail in the accompanying document, the Task Force hereby recommends that the Legislature amend the FHCDA to include decisions regarding hospice care. In the coming months, the Task Force will continue to explore the legal and ethical dimensions of extending the FHCDA's surrogate decision-making authority to other care settings and will provide additional recommendations on these issues to the Legislature.

Thank you for your attention to this matter, and for entrusting the Task Force with this important project. We look forward to working with you in the future.

Sincerely,

Beth E. Roxland, J.D., M.Bioethics
Executive Director
New York State Task Force on Life and the Law

Enclosure

cc: Richard F. Daines, M.D., Commissioner, New York State Department of Health
Honorable Thomas K. Duane, Chair, New York State Senate Health Committee
Honorable Kemp Hannon, Ranking Member, New York State Senate Health Committee
Honorable Richard N. Gottfried, Chair, New York State Assembly Committee on Health
Honorable James G. Bacalles, Ranking Member, New York State Assembly Committee on Health