







# **When we have no voice: The Family Health Care Decisions Act (FHCDA)**

**Team 1, Cohort III, CHF Health Leadership Fellows Program  
A program of the Community Health Foundation of Western & Central New York**



**April 27, 2009**

## **TEAM I MEMBERS**

-  **Nancy Blaschak**  
Executive Director, American Red Cross, Greater Buffalo Chapter
-  **Gina Fedele**  
President, GB Consulting
-  **Carol Mahoney**  
Chief Executive Officer, Community Care of Western New York
-  **Daniel McCormack**  
Executive Director, Mercy Hospital Foundation, Buffalo
-  **Roberta Rifkin**  
Vice President, Governmental Affairs, Independent Health
-  **Carrie Whitwood**  
Executive Director, Allegany/Western Steuben Rural Health Network

## **ACKNOWLEDGEMENTS**

*We would like to extend our appreciation to all those who offered their time and expertise with this project:*

### **Team Advisor**

Angel Alfonso (Lito) Gutierrez, MD, FACP

### **Community Partners**

Patricia B. Bomba, MD, FACP, Vice President and Medical Director, Geriatrics,  
Excellus BlueCross BlueShield

Christine Klotz, MHA, Advisor, Programs for the Frail Elderly, Community Health  
Foundation of Western and Central New York

Jack Freer, M.D., Hospice Care and Palliative Medicine, Internal Medicine  
Assemblyman Robin Schimminger, 140<sup>th</sup> District

Sandra Marchione, Special Assistant to Assemblyman Robin Schimminger

### **Research Assistance**

Syracuse University, Maxwell School

Tom Dennison, PhD

Jane Gelbmann, Researcher

Nicole Staring, Researcher

## **EXECUTIVE SUMMARY**

“We live in a time when medical technology can extend life well beyond what many would want. Without the legal right to refuse treatment at some point, medical technology can impose enormous personal burden and suffering on the very patients the technology was intended to aid. Every day vital health care and treatment decisions are being made in New York State by persons other than health care agents on behalf of incapacitated patients.” (*From The Committee on Health Law and the Committee on Bioethical Issues of the Association of the Bar of the City of New York, Position Paper #032006, March 20, 2006*)

Our team project evolved from many exercises and discussions that we had around health care decision making for the elderly. Having two team members that represented WNY hospices, it was a discussion filled with compassion and knowledge of what happens to individuals who neglect to assign a health care proxy and who may suddenly be unable to make decisions for themselves. Often times these individuals are subjected to unnecessary, futile treatments when their preference for palliative care would have improved their quality of life in their last days or weeks.

The right care at the right place at the right time became a very important issue and the underlying theme for our project.

As we learned more about advance directives we became aware of the Family Health Care Decisions Act. The Family Health Care Decisions Act was first introduced fifteen years ago in the New York State Legislature, but has yet to be enacted. The legislation would empower loved ones to act in the absence of a health care proxy, determine who should legally be vested with the decision-making authority, and provide what criteria should be used for making those decisions. New York is one of only two states that does not have such a law on its books.

Our vision became “ensuring that all people have a voice in their health care decisions, even when they are unable to speak for themselves.”

Our team’s project focused around creating an advocacy campaign to support passage of the Family Health Care Decisions Act as an integral component of the advance directives continuum.

The Family Health Care Decisions Act (FHCDA), awaiting passage by the NYS Legislature since 1994, was reintroduced in the current legislative session as Senate Bill #3164 (Appendix-1).

## THE ISSUE

Family members in New York do not have legal authority to consent or object to medical treatment for a patient who lacks decision-making capacity unless officially designated in advance. Hospitals and other providers customarily turn to close family members for agreement, but only courts, or court appointed guardians and health care agents appointed pursuant to a health care proxy have actual legal authority. Absent a health care proxy or living will, a physician is the legal decision-maker for a patient who lacks the ability to give consent. “Without clear and convincing evidence or a proxy, no one, not the patient’s family, not the physician, not even a court has the authority to withhold or withdraw life-sustaining treatment.” (*NYS Assembly Health Committee Hearing, December 8, 2005, Carl Coleman Testimony, at pg. 11-12, lines 12-23*)

Unfortunately, many people never leave evidence sufficient to meet this standard, the highest evidentiary standard available in a civil case. Research has established that most New Yorkers do not have a health care proxy or form of advance directive which puts them at risk for not having their wishes followed in the event they are no longer able to speak for themselves. The current standard presents an insurmountable obstacle and is no longer used by the majority of states. However, New York State adheres to this draconian expectation.

Alarming, it is apparent that there is a pervasive lack of public awareness of the clear and convincing evidence standard. The Family Health Care Decisions Act (FHCDA) puts into place a mechanism to help determine who may make a decision in accordance with the patient’s wishes where the patient cannot express these wishes. The FHCDA is not purporting to change the law. Instead, it is putting a statutory scheme in place that would act in the absence of a decision-maker.

Main reasons why this legislation is vitally important to New Yorkers include the following:

- Many adults do not contemplate their needs for end of life care.
- Many adults never leave precise instructions about their wishes.
- Most adults have not completed a health care proxy.
- Changing demographics (baby boomers) will leave many aged without live-in caregivers.
- Currently the doctor is the third party for decisions regarding healthcare and treatment for incapacitated adults.
- A doctor is bound by his/her own creed and the creed of the hospital or facility where he/she works; the patient’s wishes may be contrary to that creed.
- Current state of the law places physicians, lawyers and other medical staff at odds with the required standards.
- Patients’ end of life quality often means avoiding inappropriate prolongation of dying and relieving burden on loved ones.
- Little attention is paid to family needs, especially cost of care, when futile treatments are initiated.

- Only about half of all Americans think the healthcare system does a good or excellent job of involving dying patients and their families in major decisions about their care.
- Of the 75,000 who die in NY healthcare institutions each year, only 20% of them have a health care proxy.
- We live in a time when medical technology can extend life well beyond what many would want.
- The incapacitated person is often subject to intrusive, painful and futile medical procedures.
- The impact on families is enormous both emotionally and financially.

The Family Health Care Decisions Act:

- Protects those that have no families/friends;
- Addresses the individuals' values, and religious beliefs; and
- Establishes clear procedures for selecting a surrogate, ensuring that an incapacitated person would receive the health care treatment he/she would choose (wishes are respected).

## **SHORT TERM OUTCOMES**

The following short-term outcomes demonstrate what our project was able to change and influence through activities both inter and intra organizationally.

1. Through a survey, determined amongst our fellow cohort members (other health care professionals) that there was a lack of appreciation that families do not have the ability to make decisions on behalf of their loved ones; development of our project's premise was strengthened by this information.
2. Developed an advocacy effort to support the passage of the FHCDA which included:
  - a. Redesign of the advocacy section of the Compassion and Support website which is focused on advance directives ([www.compassionandsupport.org](http://www.compassionandsupport.org))
  - b. Greater access for information on advance directives and specifically the FHCDA
  - c. Created greater awareness of the FHCDA through networking with key stakeholders
3. Informed colleagues of the importance of advance directives.
4. Promoted advance directives and expanded the CHFWCNY Sharing Your Wishes initiative through the distribution of Sharing Your Wishes Booklet and a health file.
5. Created and distributed an advocacy letter to demonstrate the support of this issue to legislators.
6. Created and distributed an advocacy letter to encourage support of this issue through a "Letter to the Editor" throughout Western New York.
7. Trained St. Bonaventure Students enrolled in Gerontology studies, in collaboration with The Bogoni Center, on advance directives.

8. Participated and contributed to New York States coordinated efforts to promote the National Health Care Decisions Making Day:
  - a. Influenced activities to promote advance directives at Independent Health to employees, providers and members
  - b. Distributed the Sharing Your Wishes booklets at American Red Cross Blood Drives
  - c. Hosted a MOLST training in Cattaraugus County
  - d. Distributed information on advance directives on three college campus in Allegany County

## **LONG TERM IMPACT/OUTCOMES FOR FRAIL ELDERLY OR CHILDREN OF POVERTY**

The population of New York State is expected to grow 3.3% during the period 2005 to 2025, a fairly small increase over the course of 20 years. However, changes in the actual composition of the population are substantial, including the increased proportion of the elderly resulting from both the continuing increase in life expectancy and, most importantly, the aging of baby boomers. In particular, the number of residents over the age of 60 is projected to increase by 52.6%.

Education regarding the advance directives continuum, and ultimately its application, will be instrumental to ensure that care reflecting wishes and values of frail elders when they can no longer speak for themselves is carried out. The same is true for all New York Citizens.

With the foundation of the Family Health Care Decisions Act, greater emphasis can be placed on the completion of health care proxies and advance directives.

## **METHODOLOGY FOR ACHIEVEMENT**

We began in February 2008 with an assessment of our team's strengths and challenges, both individually and collectively. Using multi-voting and a "bucket list" we identified the following:

Common Challenges - Service/Delivery System; Technology and Data; and Personnel/Governance

Common Strengths - Service; Personnel/Governance; and Marketing

From there, our methodology proceeded along a timeline:

- June 11. The first concept: "The right care in the right place at the right time." Proceeding from the shared belief that hospice care is an extremely beneficial, but underutilized service, we began exploring barriers to entry.
- June 24. Narrow the focus: Recognizing that the population which would be eligible for hospice was too large and too diverse to build a project around, we looked to target an appropriate population segment.

- July 23. A new idea: While we continued to grapple with the potential scope of our project, an alternative idea emerged. If we, as Fellows, benefited from access to an executive coach, could a project be built around “Health Coaches” who would assist each fellow in the cohort with the development of a personal Health Risk Assessment (HRA)?
- August 20. Synthesis! As we discussed the use of HRA’s, we realized that we might have it both ways: we could expand the utilization of hospice care through Health Coaching and Health Risk Assessments that included advance directives for end-of-life care.
- September 4. Getting our hands around it: Before we could tackle any project involving end-of-life care, we needed a better understanding of advance directives, health care proxies, and the Sharing Your Wishes initiative.
- September 18. Advocacy across the continuum: Our understanding of the advance directives “continuum” brought us to the awareness of the considerable gaps in the continuum where an individual’s end-of-life wishes are not realized and cannot be realized. We began to look to passage of the Family Health Care Decisions Act as a critical fail-safe.
- October 1. Countdown: To prepare for our project presentation, we utilized Survey Monkey to query our CHF fellows cohort about whether they had “shared their wishes” through a health care proxy or living will.
- October 6. Our vision: From our discussions and survey findings, a broad project vision emerged: “Ensuring that all people have a voice in their health care decisions, even when they are unable to speak for themselves.”

From this vision, we articulated a project: **An advocacy campaign to support passage of the Family Health Care Decisions Act as an integral component of the advance directives continuum**

On Monday, December 8, our team had two important meetings. First, we met with Dr. Patricia Bomba, Vice President & Medical Director of Geriatrics for Excellus Blue Cross Blue Shield, and a leading statewide advocate for appropriate end-of-life decision-making. Second, we met with Assemblyman Robin Schimminger, a key sponsor and supporter of the FHCDA.

The meeting with Dr. Bomba was critical in our project methodology because we learned that our efforts would not have to start from scratch; we could stand on the shoulders of others and collaborate as part of an ongoing statewide effort to reintroduce and pass this legislation.

We engaged two researchers from the Maxwell School of Syracuse University and assigned them the following tasks (Appendix-2):

- 1) Identify NYS cases that tell the story of the importance of the FHDA, exposing cases that highlight aggressive, and unnecessarily burdensome medical treatments.
- 2) Research quality of care at end-of-life as it relates to palliative care vs. aggressive therapies

While the research was being conducted, our methodology then proceeded to the development of a Project Task Plan. The task plan helped to narrow our focus and avoid “scope creep.” This effort led directly into our Project Design.

## **Project Design**

In designing the project, we wanted to incorporate what we had learned from the research, as well as complement those efforts that were already underway in support of the Family Health Care Decisions Act. From Nicole Staring’s research about the FHCD, we know that there is strong support around the state by both groups and individuals, with only a handful of organizations that have expressed opposition. In fact, we found close to fifty organizations in support of the FHCD in New York that were connected to [www.familyhealthdecisions.org](http://www.familyhealthdecisions.org).

Our group had a number of people who work regularly with elected officials on various health care issues, and so we knew that an effective way to influence elected officials is to let the voices of their constituents be heard. Traditionally, “voices” have been heard through letters, phone calls, town hall meetings, etc. With technology, it is a lot easier and also quite effective to gather “voices” electronically in support of an issue.

We also know that there are many electronic avenues out there and that our best approach would be to partner with an existing effort. Dr. Pat Bomba has constructed a website to support her efforts with advance care planning located at [www.compassionandsupport.org](http://www.compassionandsupport.org). When we reviewed the website, it did have a legislative/advocacy section, but it was clearly not as effective or accessible as it might be to enhance its impact.

Our group worked with Dr. Bomba and her team and proposed the following redesign for the site:

### **Proposed Design for Compassionandsupport.com**

1. ***Revise “Legislation” button to read “Laws & Regs”***
  - a. By clicking on Laws & Regs you could access the various NY State laws and regulations related to advance care decision-making.
  - b. This section will be regularly updated to include new NY State rules.
  - c. This will be seen as a valuable resource by providers and caregivers.
  
2. ***Add “Advocacy/Take Action” button on the rainbow***
  - a. By clicking this button, you will be able to go directly to an advocacy page.
  - b. This button allows those who want to get involved in supporting legislation and other activities in support of advance care decision-making to make decisive action.

### 3. **The Advocacy/Take Action Front Page**

- a. On the front page there will be three categories that will lead to additional links/pages
  - i. **Why become an advocate?** This section will make the case for being an advocate by including stories, as well as testimony, demonstrating the need. There will be a short paragraph that says “Become an advocate for health care decision-making. Ensure that all people have a voice in their health care decisions, even when they cannot speak for themselves.” You can click on “Why be an advocate” and go to the following:
    1. Stories of people that are provided through the website
    2. Testimony that is given during hearings
  - ii. **What should I advocate for?** This section will include the proposed legislation and regulations that support decision-making. The opening paragraph will include a sentence or two about the Family Health Care Decisions Act and the legislation regarding Nurse Practitioner Signing DNR Orders. You can click on the “What should I advocate for” and go to the following:
    1. Further explanation of the Family Health Care Decisions Act, along with a connection to a text of the bill and other appropriate materials.
    2. Further explanation of the Nurse Practitioner Signing DNR Orders, along with a text of the proposed bill and other appropriate materials.
    3. Other bills and regulations when appropriate
  - iii. **How should I advocate?** This section will explain how you can advocate by letting your elected officials know how you feel through letters, phone calls or visits, or by joining an organization that supports this issue and aligns with your views. You will be able to click on “Let your voices be heard” in the opening paragraph on this page and you will go to a page that will provide you with:
    1. information about how to contact your legislator;
    2. text of an advocacy letter; and
    3. connection to legislators.

If you simply want to join an organization you can click on a statement in the opening paragraph that will say “Join an organization” and you will be connected to lists and links to interested organizations (a comparison study of additional links related to this topic was shared with Dr. Bomba).

In the website design enhancements proposed, we were able to emphasize the lessons we learned regarding the importance of story telling to motivate people, of providing a venue for people to contact their legislators, and providing connection to other organizations.

Dr. Bomba shared this design proposal with a working group on the FHCDA that she put together as part of the NY State Coalition for the Health Care Decisions Making Day, and much of it will be incorporated. Our Team also provided her group with a draft of a letter to legislators in support of the FHCDA, which will be posted for all to use.

## **OUTCOME MEASUREMENT AND SUSTAINABILITY/NEXT STEPS**

Although it has been 15 years since the FHCDA was first considered by the NYS legislature, this year offers the greatest opportunity for passage. In the past 15 years, the Senate, which had a Republican majority, was instrumental in preventing passage. This past election put Senate Democrats in the majority for the first time since this bill was introduced.

Through our active involvement and collaboration with many key constituency groups and individuals, this project influenced infrastructure changes and expanded resources that have been incorporated into systems that will be used in the future:

1. In September 2008, our Team conducted an online survey with colleagues in Cohort III of the Community Health Foundation's Health Leadership Fellows Program to get a baseline from other health care providers on the completion of a health care proxy; whether they discussed their end-of life wishes with a designated health care proxy/agent; whether each member of their family over 18 had completed a health care proxy; and their opinion on: "If someone does not have a designated health care proxy/agent and is unable to communicate their wishes, a member of their family should be legally able to make health care decisions for them".
  - Outcome Measurement: 35 completed the survey; 64.7% had a health care proxy; 60% had expressed their wishes for life-sustaining treatment; 17.1% indicated that each member of their immediate family over the age of 18 has completed a health care proxy document; and 88.2% stated that a family member should be legally able to make decisions on the behalf of someone in the absence of a health care proxy.
  - Sustainability/Next Steps: A week after the presentation on April 27<sup>th</sup> to the Cohort, a follow-up survey will be conducted for comparison to the baseline. We will utilize the FAN to distribute information on health care proxies with a link to the Compassion and Support and the Sharing Your Wishes websites.
  
2. Self-Engagement Support – expanded awareness and engagement among colleagues and other key constituency groups on the need to pass the Family Health Care Decisions Act in New York State, as it will serve as a safety-net for those who may not have executed a health care proxy
  - Outcome Measurement: Through networking and collaboration, members of our Team and this project provided resources and influenced action in both the ***New York State National Healthcare Decisions Day Coalition*** and the ***Family Health Care Decisions Act (FHCDA) Subgroup***

- Sustainability/Next Steps: The information and advocacy efforts on [www.compassionandsupport.org](http://www.compassionandsupport.org) can be used by this group to support passage of the bill.
3. Delivery System Design – assisted in the expansion of the technology infrastructure on the widely recognized [www.compassionandsupport.org](http://www.compassionandsupport.org) website that can be expanded in the future to encompass other issues related to end-of-life (Appendix-3)
- Outcome Measurement: The Compassion and Support website has increased capabilities that will improve navigation and access to advocacy information on the Family Health Care Decisions Act
  - Sustainability/Next Steps: Through the expanded infrastructure of the website, this resource can support other related advocacy issues
4. Resources and Tool Development\* – developed tools and resources that can be utilized by those outside of our Team to support the continuation of activities that will advocate for the advance directives continuum, specifically the Family Health Care Decisions Act
- Outcome Measurement and Sustainability/Next Steps:
    - Letter to the Editor – developed and published in the Buffalo News, Olean Times Herald, Batavia Daily News, Jamestown Post Journal, and West Seneca Bee, with others yet to be confirmed (Appendix-4)
    - Letter to Legislators – template developed and placed on the Compassion and Support website.
    - Constituency Group comparison between the Compassion and Support, and the Family Decisions websites that was used by each group to expand their listings.
    - Connection to Legislators – capability proposed for a link to an e-advocacy page from the Compassion and Support website that allows people to contact their elected officials.

## **IOM CORE COMPETENCIES**

**1. Provide patient centered care** – *identify, respect, and care about patients' differences, values, preferences, and expressed needs; relieve pain and suffering; coordinate continuous care; listen to, clearly inform, communicate with, and educate patients; share decision making and management; and continuously advocate disease prevention, wellness, and promotion of healthy lifestyles, including a focus on population health.*

As the project is focused on the concept of all persons having an opportunity and pathway to express their wishes regarding care by proxy, even in the unfortunate absence of formal document, this competency is central to its theme and purpose. The Family Health Care Decisions Act provides for legal authority to insure that expressed personal choices are respected and observed. In ideal circumstances, constructing a living will and designating a health care proxy to whom decision-making is delegated when an individual can no longer speak for him/herself, reflects the essence of patient centered care. It is recognized, however, that communication of values and preferences is a key matter, whether to an officially designated health care proxy, or to a family member who could, provided appropriate law is in place, insure that desires are upheld. These include actions specific to treatment options available for the relief of pain and suffering and the respect of individual values and preferences. The Family Health Care Decisions Act recognizes the significance of discussions and expressed desires regarding health care preferences that individuals have with one another and that such conversations have a worthy place in determining a course of intervention. Further, such representations with respect to patient centered care should have a more profound place than those resulting from the mere designation of a proxy without accompanying communication or instruction regarding end of life care wishes.

**2. Work in interdisciplinary teams** – *cooperate, collaborate, communicate, and integrate care in teams to ensure that care is continuous and reliable.*

Team One is represented by a cross-section of disciplines, experience, and expertise with regard to program design and work with constituents relevant to the project. All project team members identified areas of strength and roles within the collaborative effort to insure positive, productive contributions. Specialized skills were offered by team members to enhance the team process, learning, and progress toward project goals. Opportunities were made available to visit team member agencies, with distances presenting some barriers. Meetings were held in alternative locations as needed and often by conference call. The resources of team member agencies were accessed to enhance task completion and augment aspects of the project's focus. Team One worked collaboratively to prepare the project report and presentation, both as a full team and in smaller groups for specified tasks.

**3. Employ evidence-based practice** – *integrate best research with clinical expertise and patient values for optimum care, and participate in learning and research activities to the extent feasible. Furthermore, practicing evidence-based medicine requires clinical expertise, but also expertise in retrieving, interpreting, and applying the results of scientific studies and in communicating the risks and benefits of different course of action to patients.*

New York State has remained as one of two states in the nation that has not adopted legislation reflecting the intent of the Family Health Care Decisions Act. Research was conducted by graduate students of the Maxwell School at Syracuse University under the direction of Tom Dennison to assist Team One in understanding the issues surrounding lack of support and barriers to date for this legislation, including stories relating to the absence of provisions for family decision-making.

Team One seeks to educate others via its work with the Compassion and Support website, as well as in materials for establishing a health care proxy and expression of end of life wishes for care, with regard to the risks and benefits related to end of life decision-making.

**4. Apply quality improvement** – *identify errors and hazards in care; understand and implement basic safety design principles, such as standardization and simplification; continually understand and measure quality of care in terms of structure, process, and outcomes in relation to patient and community needs; design and test interventions to change processes and systems of care, with the objective of improving quality.*

The project seeks to improve quality of care for persons who are not able to speak for themselves by encouraging methodologies wherein this may be effectively accomplished. Establishing a health care proxy with verbal and written communication of desired actions and treatments, engaged at a time when life threatening circumstances are occurring, addresses process and consideration of outcomes in a structured manner. Alternatives to care can be considered at the time a health care proxy is established, including the exploration of consequences of various actions, at a distance from the stressors that occur when such decisions are pressed in the midst of tragic or sudden events. The Family Health Care Decisions Act seeks to establish both standardization and protections for individuals who have made their health care preferences known. The opportunity to have thoughtful communication expressed when needed, whether through formal proxy or via family member representative, reduces the occurrence and likelihood of inappropriate care decisions being made, some with unnecessary, harmful or costly outcomes. The project seeks not only the passage of the Family Health Care Decisions Act, but the increased utilization of the health care proxy and living will directives for end of life care as a standardized and simplified means to increase positive, desired outcomes for individuals.

**5. Utilize informatics – communicate, manage knowledge, mitigate error, and support decision making using information and technology.**

A significant part of the project design incorporated web-based technology to inform individuals about end of life care decision-making options. By assisting in the design of informational materials on the [www.compassionandsupport.org](http://www.compassionandsupport.org) website, a consistent message has been made possible with regard to advocacy for the Family Health Care Decisions Act. Due to integrated web page design changes, visitors to the site will receive clear information in support of choices that can be made for communication with legislators, as well as care decisions. An online survey tool (Survey Monkey) was employed early in the project to gather baseline data on Cohort member understanding of family limitations in care decision-making. Throughout the project, team members have also communicated and managed information relating to the project using various forms of technology. Our colleague, Dr. Pat Bomba was exposed to the use of an online advocacy tool through our involvement and will link her website to the MSSNY website for online advocacy of the Family Healthcare Decisions Act and future advance directives issues. In addition, we have discussed utilizing our respective databases to send emails to increase awareness about this important piece of legislation. A secure web portal in which to store advance directives online called Assuring Your Wishes was brought to the attention of Dr. Bomba and she is promoting its use. It can be found at [www.assuringyourwishes.org](http://www.assuringyourwishes.org) and is available to house advance directives so they are available to providers and caregivers in the event an individual becomes incapacitated. The distance between team members has encouraged creative means for maintaining positive communications, including telephone conferencing with simultaneous computer access for discussion of materials. This has resulted in consistency of information utilized to support decision making for project direction and design, historical documentation, and research review. Materials selected for distribution represent researched options adapted for the project to provide consistency with information currently available in the community and reduce potential for error.

## **INTER-ORGANIZATIONAL COLLABORATION**

From the beginnings of our team collaboration, the diversity of our representation enhanced discussions on how we might find passion individually on a selected project. Except for two organizations that had naturally occurring collaborative work from time-to-time, there was little formal relationship amongst or between team members' organizations. The initial concept discussions were sensitive to the inter-organizational similarities that did exist and focused on these, but ultimately it was our differences that became the impetus for narrowing the population and purpose of study. Because of candid conversation about our organizational work and personal or professional passions that came about in connection to that work, the project found a path. This was significantly enhanced by personal experiences with advance directives and by shared relationships with college-aged children as it touched on this subject.

What the team discovered and embraced as its strengths, presented naturally by individual leaders or revealed and encouraged by team members, fostered the execution of the work needing to be accomplished. The outcomes of the project were significantly enhanced by roles within the team and the wide scope of knowledge and experience within health care delivery that could be shared, adding new dimensions for consideration at every turn. The assets brought forward to the team table are also acknowledged as both personal and those represented in the capacities of our organizations, including the support of our governing boards. The relationships that "make the whole greater than the sum of its parts" as a team also assisted in outreach to others for an expanded collaboration.

During the course of our project, we were able to reach out to a number of organizations and individuals that are key thought leaders in the area of the advance directives continuum. Whether we worked with them in terms of cooperation or coordination, learning from their experience in the field, as well as offering our time and expertise, we were able to share important information.

There is no doubt that what emerged from each individual relationship that was fostered was far greater than what each of us as stakeholders could have accomplished individually. This was true collaboration. The following people contributed to our project:

**Christine Klotz, MHA**, Advisor for Programs for the Frail Elderly, Community Health Foundation of Central and Western New York – Ms. Klotz's responsibility for projects in the Central and Western New York communities dealing with health decisions and Advance Care Planning as well as her leadership surrounding the Sharing Your Wishes initiative was a key turning point in determining the direction of our project. An appreciation of the challenges that this initiative has faced enabled us to explore how we could tie the general topic of health care proxies into the project that would ultimately focus on advocacy of the Family Health Care Decisions Act.

**Jack P. Freer, MD**, Hospice Care and Palliative Care Medicine, Internal Medicine, Buffalo, NY – His background and insight into the Family Healthcare Decisions Act was incomparable. He helped to steer our project toward further collaboration with Dr. Patricia Bomba. In addition, through our team's prompting, Dr. Freer delivered testimony before legislators at the Cheektowaga Town Hall meeting.

**Patricia Bomba, MD, FACP**, Vice President and Medical Director for Geriatrics, Univera Healthcare – As Director of a community wide palliative care initiative in Rochester, she was successful in the monumental passage of the Medical Orders for Life-sustaining Treatment legislation which subsequently has been made a NY standard. Her passion for advance directives and the corresponding website that she manages led us to understand that hers was the most comprehensive website on the topic in New York State.

We made a decision to work with Dr. Bomba to make her website more user friendly for advocacy purposes. A number of changes have been recommended, including a link to electronic advocacy.

**Assemblyman Robin Schimminger, 140<sup>th</sup> District and his Special Assistant Sandy Marchione** – The meeting helped us to understand the legislative process, as well as this Assemblyman's desire to improve healthcare in our state. It became ever more apparent that there was a need for further education surrounding the importance of the passage of the Family Health Care Decisions Act.

## **LESSONS LEARNED**

Our Team met to specifically address “Lessons Learned” and had a great discussion. We acknowledged that there had been a consistent theme to our group process that ultimately led us to a project that reflects those themes as well. The three themes that have emerged throughout our group process are self-awareness, communication and respect.

We began our journey through the Fellowship program with an opportunity to develop self awareness from our 360 feedback, initial coaching sessions, Myers Briggs results and the opportunity to work within our new team to seek more input and advice. We all agreed that the gift of self-awareness contributes to the overall functioning of a group. The “bull in the china shop effect” is minimized when one understands self. The professional coaching opportunities, as well as input from our Team, have been a great help to us all. Some of our members remarked that the past several months have been the most difficult in their careers. The Fellowship experience and the relationships developed as a result have helped us all through those changes. To quote a group member: “This experience has allowed me to find a sense of normalcy. I went through the most challenging time in my work life during our fellowship. I found a footing here.”

Communication has been key to the successful development of our project. The geographic distances which separated the team members limited the number of face-to-face meetings that we were able to have; most of our intersession and project meetings were held via conference call. When we met we maximized the opportunity. An agenda guided the discussion and a designated facilitator ensured that we remained focused on the tasks at hand. Our discussions—and our disagreements—were marked by a great degree of civility and collegiality. We recognized the importance of each meeting and were not distracted with conflict or discord. We took a very structured and systematic approach to our work as a group. Members took on key roles; we all agreed that everyone was an active participant and a contributor to the group's success. A complete record was kept of our meetings through detailed minutes. It was easy to keep track of what was happening with the group between meetings or if someone missed a meeting (which was rare – everyone has made a point to attend meetings regularly and via conference call if necessary).

We learned that real change takes time. Although we began with big ideas we had to limit the scope of the project due to time constraints. We could have approached this issue on our own; however, we decided to fold our work into an effort that has already been underway for some time. We felt that the best use of our efforts would be to move an already established program forward rather than begin something that we would most likely not finish ourselves.

Throughout the Fellowship experience, we were reminded that leadership is about respect and appreciating differences. It is about developing a willingness to take the best someone has to offer, listening and hearing what others are saying and being able to incorporate that into something you may think differently about. We took the time to learn from one another. We scheduled meetings at our office locations so that each group member (except one) was able to introduce his/her organization to the group. We developed an appreciation for the work that we each do in the community. We had presentations on a few occasions from group members that had a particular expertise to share with all of us. We feel that we were able to tap into the strengths that the individual group members brought to the table to make our group function efficiently. No one had an agenda here – we all made a commitment to the Fellowship, the group experience and the project. Reflecting back on this experience those were the most important outcomes. Individual differences or disagreements were never allowed to get in the way of the group agenda. We believe the result is a project of which we can all be proud.

The project speaks to the critical importance of self-awareness when it comes to knowing what the options are for end of life care and what we want to have happen for ourselves. The relevant questions need to be asked and thoughtfully considered at a time ideally free from stressful circumstances. We also know that our wishes need to be communicated in a manner that is clear and concise, and assures that our voice will be heard if and when we cannot speak for ourselves. The FHODA presents an opportunity for these assurances when others may be lost. And, finally, the project is about respect for another's decision and articulated desires. We may not always agree with the choices or decisions that exist among us and have debated these at length, but we understand our responsibility and obligation to respect them.

## **BIBLIOGRAPHY AND RESEARCH**

### **The Maxwell School of Citizenship and Public Affairs Request for Research Assistance**

**Team Project Topic:** Develop educational materials and program for New York State legislators and their staff so that they can appreciate the important role that the New York State Family Health Care Decisions Act A6993-A/S5522 can play in supporting patient centered care.

**Summary of type of support needed and the team's expectations of the support:**

The team requests research assistance to assist with developing an educational strategy for the support of the Family Healthcare Decisions Act.

**Assumption 1** In New York State, absent a health care proxy, an individual cannot have their medical treatment wishes followed when they are not able to communicate those wishes, even if they have had conversations regarding their treatment wishes with family members.

**Assumption 2** The majority of New Yorkers believe that, absent a health care proxy, there is legislation in place that allows family members to make medical treatment decisions on their behalf when they are not able to communicate those wishes. This legislation does not exist.

**Assumption 3** The presence of legislation allowing family members and close friends to make medical treatment decisions, including decisions surrounding the use of artificial life-sustaining treatment when an individual no longer has decision-making capacity, will increase the opportunity for quality, person-centered medical treatment decisions to be made.

**Goal:** To develop an educational campaign directed at NYS legislators and their staff that builds a foundation to support the advance directives continuum with the FHDA.

**Research Requested (Appendix-2)**

**Phase One** Identify NYS cases that tell the story of the importance of the FHDA, exposing cases that highlight aggressive, and unnecessarily burdensome medical treatments. This research will also identify constituency groups that have intervened in medical treatment cases where there is a lack of family decision-making authority.

**Phase Two** Research quality of care at end-of-life as it relates to palliative care versus aggressive therapies including life sustaining medical treatment.

Quantitative: Research data on the current experience (and related costs) in NYS related to aggressive, clinical interventions during the last weeks of life such as chemotherapy and burdensome artificial life sustaining treatments.

Qualitative: Research on palliative care vs. aggressive medical treatments as it relates to patient-centered care and the respective perceptions of greater quality of life for these patients. Include comparative cost data as may be available.

## **APPENDIX**

1 – State of New York introduced Senate Bill #3164

2 – Research and Bibliography

Nicole Staring, Researcher  
Syracuse University, Maxwell School

Jane Gelbmann, Researcher  
Syracuse University, Maxwell School

3 – “Before and After” screen shots of the [www.compassionandsupport.org](http://www.compassionandsupport.org) as of  
April 14, 2009

4 - Published “Letters to the Editor”

Batavia News  
Buffalo News  
Jamestown Post-Journal  
Olean Times Herald

**APPENDIX-1: State of New York introduced Senate Bill #3164**

**Text - S03164**

S T A T E O F N E W Y O R K

3164

2009-2010 Regular Sessions

I N S E N A T E

March 12, 2009

Introduced by Sen. DUANE -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT to amend the public health law, in relation to establishing procedures for making medical treatment decisions on behalf of persons who lack the capacity to decide about treatment for themselves and to repeal certain provisions of such law relating thereto

THE PEOPLE OF THE STATE OF NEW YORK, REPRESENTED IN SENATE AND ASSEMBLY, DO ENACT AS FOLLOWS:

1 Section 1. Legislative intent. Under article 29-C of the public health  
2 law, competent adults have a powerful way to control their medical  
3 treatment even after they lose decision-making capacity, by appointing  
4 someone they trust to decide on their behalf. This legislation fills a  
5 gap that remains in New York law. It adds, inter alia, a new article  
6 29-CC to the public health law, which establishes a decision-making  
7 process whereby a surrogate is selected and empowered to make health  
8 care decisions for patients who lack capacity to make their own health  
9 care decisions and who have not otherwise appointed an agent to make  
10 health care decisions pursuant to article 29-C of the public health law  
11 or provided clear and convincing evidence of their treatment wishes.

12 The legislature does not intend to encourage or discourage any partic-  
13 ular health care decision or treatment, or to create or expand a  
14 substantive right of competent adults to decide about treatment for  
15 themselves. Further, the legislature does not intend to authorize a  
16 surrogate to deny to the patient personal services that every patient  
17 would generally receive, such as appropriate food, water, bed rest, room  
18 temperature and hygiene. This legislation establishes a procedure to  
19 facilitate responsible decision-making by surrogates on behalf of  
20 patients who do not have capacity to make their own health care deci-  
21 sions.

22 This legislation affirms existing laws and policies that limit indi-  
23 vidual conduct of patients with or without capacity, including those

EXPLANATION--Matter in ITALICS (underscored) is new; matter in brackets  
[ ] is old law to be omitted.

LBD05935-01-9

1 laws and policies against homicide, suicide, assisted suicide and mercy  
2 killing.

3 S 2. The public health law is amended by adding two new articles 29-CC  
4 and 29-CCC to read as follows:

5 ARTICLE 29-CC

6 FAMILY HEALTH CARE DECISIONS ACT

7 SECTION 2994-A. DEFINITIONS.

8 2994-B. PRIORITY OF DECISION BY HEALTH CARE AGENT AND ARTICLE  
9 SEVENTEEN-A GUARDIAN.

10 2994-C. DETERMINATION OF INCAPACITY.

11 2994-D. HEALTH CARE DECISIONS FOR ADULT PATIENTS BY SURROGATES.

12 2994-E. DECISIONS ABOUT LIFE-SUSTAINING TREATMENT FOR MINOR  
13 PATIENTS.

14 2994-F. OBLIGATIONS OF ATTENDING PHYSICIAN.

15 2994-G. HEALTH CARE DECISIONS FOR ADULT PATIENTS WITHOUT SURRO-  
16 GATES.

17 2994-H. DECISIONS FOR PATIENTS TRANSFERRED FROM A MENTAL HYGIENE  
18 FACILITY.

19 2994-I. SPECIFIC POLICIES FOR ORDERS NOT TO RESUSCITATE.

20 2994-J. REVOCATION OF CONSENT.

21 2994-K. IMPLEMENTATION AND REVIEW OF DECISIONS.

22 2994-L. INTERINSTITUTIONAL TRANSFERS.

23 2994-M. ETHICS REVIEW COMMITTEES.

24 2994-N. CONSCIENCE OBJECTIONS.

25 2994-O. IMMUNITY.

26 2994-P. LIABILITY FOR HEALTH CARE COSTS.

27 2994-Q. EFFECT ON OTHER RIGHTS.

28 2994-R. SPECIAL PROCEEDING AUTHORIZED; COURT ORDERS; HEALTH CARE  
29 GUARDIAN FOR MINOR PATIENT.

30 2994-S. REMEDY.

31 2994-T. REGULATIONS.

32 2994-U. RIGHTS TO BE PUBLICIZED.

33 S 2994-A. DEFINITIONS. THE FOLLOWING WORDS OR PHRASES, USED IN THIS  
34 ARTICLE, SHALL HAVE THE FOLLOWING MEANINGS, UNLESS THE CONTEXT OTHERWISE  
35 REQUIRES:

36 1. "ADULT" MEANS ANY PERSON WHO IS EIGHTEEN YEARS OF AGE OR OLDER OR  
37 HAS MARRIED.

38 2. "ATTENDING PHYSICIAN" MEANS A PHYSICIAN, SELECTED BY OR ASSIGNED TO  
39 A PATIENT PURSUANT TO HOSPITAL POLICY, WHO HAS PRIMARY RESPONSIBILITY  
40 FOR THE TREATMENT AND CARE OF THE PATIENT. WHERE MORE THAN ONE PHYSICIAN  
41 SHARES SUCH RESPONSIBILITY, OR WHERE A PHYSICIAN IS ACTING ON THE  
42 ATTENDING PHYSICIAN'S BEHALF, ANY SUCH PHYSICIAN MAY ACT AS AN ATTENDING  
43 PHYSICIAN PURSUANT TO THIS ARTICLE.

44 3. "ETHICS REVIEW COMMITTEE" MEANS THE INTERDISCIPLINARY HOSPITAL  
45 COMMITTEE ESTABLISHED IN ACCORDANCE WITH THE REQUIREMENTS OF SECTION  
46 TWENTY-NINE HUNDRED NINETY-FOUR-M OF THIS ARTICLE.

47 4. "CARDIOPULMONARY RESUSCITATION" MEANS MEASURES, AS SPECIFIED IN  
48 REGULATIONS PROMULGATED BY THE COMMISSIONER, TO RESTORE CARDIAC FUNCTION  
49 OR TO SUPPORT VENTILATION IN THE EVENT OF A CARDIAC OR RESPIRATORY  
50 ARREST. CARDIOPULMONARY RESUSCITATION SHALL NOT INCLUDE MEASURES TO  
51 IMPROVE VENTILATION AND CARDIAC FUNCTION IN THE ABSENCE OF AN ARREST.

52 5. "CLOSE RELATIVE OR CLOSE FRIEND" MEANS ANY PERSON, EIGHTEEN YEARS  
53 OF AGE OR OLDER, WHO IS A RELATIVE OR FRIEND OF THE PATIENT, REGARDLESS  
54 OF BLOOD OR LEGAL RELATIONSHIP, AND WHO HAS MAINTAINED SUCH REGULAR  
55 CONTACT WITH THE PATIENT AS TO BE FAMILIAR WITH THE PATIENT'S ACTIV-  
56 ITIES, HEALTH, AND RELIGIOUS OR MORAL BELIEFS.

1 6. "DECISION-MAKING CAPACITY" MEANS THE ABILITY TO UNDERSTAND AND  
2 APPRECIATE THE NATURE AND CONSEQUENCES OF PROPOSED HEALTH CARE, INCLUD-  
3 ING THE BENEFITS AND RISKS OF, AND ALTERNATIVES TO, ANY SUCH PROPOSED  
4 HEALTH CARE, AND TO REACH AN INFORMED DECISION.

5 7. "DEVELOPMENTAL DISABILITY" MEANS A DEVELOPMENTAL DISABILITY AS  
6 DEFINED IN SUBDIVISION TWENTY-TWO OF SECTION 1.03 OF THE MENTAL HYGIENE  
7 LAW.

8 8. "DOMESTIC PARTNER" MEANS A PERSON WHO, WITH RESPECT TO ANOTHER  
9 PERSON:

10 (A) IS FORMALLY A PARTY IN A DOMESTIC PARTNERSHIP OR SIMILAR RELATION-  
11 SHIP WITH THE OTHER PERSON, ENTERED INTO PURSUANT TO THE LAWS OF THE  
12 UNITED STATES OR OF ANY STATE, LOCAL OR FOREIGN JURISDICTION, OR REGIS-  
13 TERED AS THE DOMESTIC PARTNER OF THE OTHER PERSON WITH ANY REGISTRY  
14 MAINTAINED BY THE EMPLOYER OF EITHER PARTY OR ANY STATE, MUNICIPALITY,  
15 OR FOREIGN JURISDICTION; OR

16 (B) IS FORMALLY RECOGNIZED AS A BENEFICIARY OR COVERED PERSON UNDER  
17 THE OTHER PERSON'S EMPLOYMENT BENEFITS OR HEALTH INSURANCE; OR

18 (C) IS DEPENDENT OR MUTUALLY INTERDEPENDENT ON THE OTHER PERSON FOR  
19 SUPPORT, AS EVIDENCED BY THE TOTALITY OF THE CIRCUMSTANCES INDICATING A  
20 MUTUAL INTENT TO BE DOMESTIC PARTNERS INCLUDING BUT NOT LIMITED TO:  
21 COMMON OWNERSHIP OR JOINT LEASING OF REAL OR PERSONAL PROPERTY; COMMON  
22 HOUSEHOLDING, SHARED INCOME OR SHARED EXPENSES; CHILDREN IN COMMON;  
23 SIGNS OF INTENT TO MARRY OR BECOME DOMESTIC PARTNERS UNDER PARAGRAPH (A)  
24 OR (B) OF THIS SUBDIVISION; OR THE LENGTH OF THE PERSONAL RELATIONSHIP  
25 OF THE PERSONS.

26 EACH PARTY TO A DOMESTIC PARTNERSHIP SHALL BE CONSIDERED TO BE THE  
27 DOMESTIC PARTNER OF THE OTHER PARTY. "DOMESTIC PARTNER" SHALL NOT  
28 INCLUDE A PERSON WHO IS RELATED TO THE OTHER PERSON BY BLOOD IN A MANNER  
29 THAT WOULD BAR MARRIAGE TO THE OTHER PERSON IN NEW YORK STATE. "DOMES-  
30 TIC PARTNER" ALSO SHALL NOT INCLUDE ANY PERSON WHO IS LESS THAN EIGHTEEN  
31 YEARS OF AGE OR WHO IS THE ADOPTED CHILD OF THE OTHER PERSON OR WHO IS  
32 RELATED BY BLOOD IN A MANNER THAT WOULD BAR MARRIAGE IN NEW YORK STATE  
33 TO A PERSON WHO IS THE LAWFUL SPOUSE OF THE OTHER PERSON.

34 9. "EMANCIPATED MINOR PATIENT" MEANS A MINOR PATIENT WHO IS THE PARENT  
35 OF A CHILD, OR WHO IS SIXTEEN YEARS OF AGE OR OLDER AND LIVING INDEPEND-  
36 ENTLY FROM HIS OR HER PARENTS OR GUARDIAN.

37 10. "GENERAL HOSPITAL" MEANS A GENERAL HOSPITAL AS DEFINED IN SUBDIVI-  
38 SION TEN OF SECTION TWENTY-EIGHT HUNDRED ONE OF THIS CHAPTER.

39 11. "GUARDIAN OF A MINOR" OR "GUARDIAN" MEANS A HEALTH CARE GUARDIAN  
40 OR A LEGAL GUARDIAN OF THE PERSON OF A MINOR.

41 12. "HEALTH CARE" MEANS ANY TREATMENT, SERVICE, OR PROCEDURE TO DIAG-  
42 NOSE OR TREAT AN INDIVIDUAL'S PHYSICAL OR MENTAL CONDITION. PROVIDING  
43 NUTRITION OR HYDRATION ORALLY, WITHOUT RELIANCE ON MEDICAL TREATMENT, IS  
44 NOT HEALTH CARE UNDER THIS ARTICLE AND IS NOT SUBJECT TO THIS ARTICLE.

45 13. "HEALTH CARE AGENT" MEANS A HEALTH CARE AGENT DESIGNATED BY AN  
46 ADULT PURSUANT TO ARTICLE TWENTY-NINE-C OF THIS CHAPTER.

47 14. "HEALTH CARE DECISION" MEANS ANY DECISION TO CONSENT OR REFUSE TO  
48 CONSENT TO HEALTH CARE.

49 15. "HEALTH CARE GUARDIAN" MEANS AN INDIVIDUAL APPOINTED BY A COURT,  
50 PURSUANT TO SUBDIVISION FOUR OF SECTION TWENTY-NINE HUNDRED  
51 NINETY-FOUR-R OF THIS ARTICLE, AS THE GUARDIAN OF A MINOR PATIENT SOLELY  
52 FOR THE PURPOSE OF DECIDING ABOUT LIFE-SUSTAINING TREATMENT PURSUANT TO  
53 THIS ARTICLE.

54 16. "HEALTH CARE PROVIDER" MEANS AN INDIVIDUAL OR FACILITY LICENSED,  
55 CERTIFIED, OR OTHERWISE AUTHORIZED OR PERMITTED BY LAW TO ADMINISTER  
56 HEALTH CARE IN THE ORDINARY COURSE OF BUSINESS OR PROFESSIONAL PRACTICE.

1 17. "HEALTH OR SOCIAL SERVICE PRACTITIONER" MEANS A REGISTERED PROFES-  
2 SIONAL NURSE, NURSE PRACTITIONER, PHYSICIAN, PHYSICIAN ASSISTANT,  
3 PSYCHOLOGIST OR CERTIFIED SOCIAL WORKER LICENSED OR CERTIFIED PURSUANT  
4 TO THE EDUCATION LAW.

5 18. "HOSPITAL" MEANS A GENERAL HOSPITAL AS DEFINED IN SUBDIVISION TEN  
6 OF SECTION TWENTY-EIGHT HUNDRED ONE OF THIS CHAPTER, AND A RESIDENTIAL  
7 HEALTH CARE FACILITY AS DEFINED IN SUBDIVISION THREE OF SECTION TWENTY-  
8 EIGHT HUNDRED ONE OF THIS CHAPTER, BUT EXCLUDING A WARD, WING, UNIT OR  
9 OTHER PART OF A GENERAL HOSPITAL THAT PROVIDES MENTAL HEALTH SERVICES TO  
10 MENTALLY ILL PERSONS PURSUANT TO AN OPERATING CERTIFICATE ISSUED BY THE  
11 COMMISSIONER OF MENTAL HEALTH OTHER THAN MEDICAL-PSYCHIATRIC UNITS  
12 JOINTLY IDENTIFIED BY THE COMMISSIONER OF HEALTH AND THE COMMISSIONER OF  
13 MENTAL HEALTH.

14 19. "LIFE-SUSTAINING TREATMENT" MEANS ANY MEDICAL TREATMENT OR PROCE-  
15 DURE WITHOUT WHICH THE PATIENT WILL DIE WITHIN A RELATIVELY SHORT TIME,  
16 AS DETERMINED BY AN ATTENDING PHYSICIAN TO A REASONABLE DEGREE OF  
17 MEDICAL CERTAINTY.

18 20. "MENTAL HYGIENE FACILITY" MEANS A RESIDENTIAL FACILITY OPERATED OR  
19 LICENSED BY THE OFFICE OF MENTAL HEALTH OR THE OFFICE OF MENTAL RETARDA-  
20 TION AND DEVELOPMENTAL DISABILITIES.

21 21. "MENTAL ILLNESS" MEANS A MENTAL ILLNESS AS DEFINED IN SUBDIVISION  
22 TWENTY OF SECTION 1.03 OF THE MENTAL HYGIENE LAW, PROVIDED, HOWEVER,  
23 THAT MENTAL ILLNESS SHALL NOT INCLUDE DEMENTIA, SUCH AS ALZHEIMER'S  
24 DISEASE, OR OTHER DISORDERS RELATED TO DEMENTIA.

25 22. "MINOR" MEANS ANY PERSON WHO IS NOT AN ADULT.

26 23. "ORDER NOT TO RESUSCITATE" MEANS AN ORDER NOT TO ATTEMPT CARDIOP-  
27 ULMONARY RESUSCITATION IN THE EVENT A PATIENT SUFFERS CARDIAC OR RESPIR-  
28 ATORY ARREST.

29 24. "PARENT", FOR THE PURPOSE OF A HEALTH CARE DECISION ABOUT A MINOR  
30 PATIENT, MEANS A PARENT WHO HAS CUSTODY OF, OR WHO HAS MAINTAINED  
31 SUBSTANTIAL AND CONTINUOUS CONTACT WITH, THE MINOR PATIENT.

32 25. "PATIENT" MEANS A PERSON ADMITTED TO A HOSPITAL.

33 26. "PERSON CONNECTED WITH THE CASE" MEANS THE PATIENT, ANY PERSON ON  
34 THE SURROGATE LIST, A PARENT OR GUARDIAN OF A MINOR PATIENT, THE HOSPI-  
35 TAL ADMINISTRATOR, AN ATTENDING PHYSICIAN, ANY OTHER HEALTH OR SOCIAL  
36 SERVICES PRACTITIONER WHO IS OR HAS BEEN DIRECTLY INVOLVED IN THE  
37 PATIENT'S CARE, AND ANY DULY AUTHORIZED STATE AGENCY, INCLUDING THE  
38 FACILITY DIRECTOR OR REGIONAL DIRECTOR FOR A PATIENT TRANSFERRED FROM A  
39 MENTAL HYGIENE FACILITY AND THE FACILITY DIRECTOR FOR A PATIENT TRANS-  
40 FERRED FROM A CORRECTIONAL FACILITY.

41 27. "REASONABLY AVAILABLE" MEANS THAT A PERSON TO BE CONTACTED CAN BE  
42 CONTACTED WITH DILIGENT EFFORTS BY AN ATTENDING PHYSICIAN, ANOTHER  
43 PERSON ACTING ON BEHALF OF AN ATTENDING PHYSICIAN, OR THE HOSPITAL.

44 28. "RESIDENTIAL HEALTH CARE FACILITY" MEANS A RESIDENTIAL HEALTH CARE  
45 FACILITY AS DEFINED IN SUBDIVISION THREE OF SECTION TWENTY-EIGHT HUNDRED  
46 ONE OF THIS CHAPTER.

47 29. "SURROGATE" MEANS THE PERSON SELECTED TO MAKE A HEALTH CARE DECI-  
48 SION ON BEHALF OF A PATIENT PURSUANT TO SECTION TWENTY-NINE HUNDRED  
49 NINETY-FOUR-D OF THIS ARTICLE.

50 30. "SURROGATE LIST" MEANS THE LIST SET FORTH IN SUBDIVISION ONE OF  
51 SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE.

52 S 2994-B. PRIORITY OF DECISION BY HEALTH CARE AGENT AND ARTICLE SEVEN-  
53 TEEN-A GUARDIAN. A HEALTH CARE DECISION BY A HEALTH CARE AGENT ON A  
54 PATIENT'S BEHALF IS GOVERNED BY ARTICLE TWENTY-NINE-C OF THIS CHAPTER  
55 AND SHALL HAVE PRIORITY OVER DECISIONS BY ANY OTHER PERSON EXCEPT THE  
56 PATIENT OR AS OTHERWISE PROVIDED IN THE HEALTH CARE PROXY. HEALTH CARE

1 PROVIDERS SHALL MAKE REASONABLE EFFORTS TO DETERMINE WHETHER THE PATIENT  
2 HAS APPOINTED A HEALTH CARE AGENT AND TO CONTACT THE AGENT BEFORE RELY-  
3 ING ON A DECISION BY A SURROGATE UNDER THIS ARTICLE.

4 S 2994-C. DETERMINATION OF INCAPACITY. 1. PRESUMPTION OF CAPACITY. FOR  
5 PURPOSES OF THIS ARTICLE, EVERY ADULT SHALL BE PRESUMED TO HAVE DECI-  
6 SION-MAKING CAPACITY UNLESS DETERMINED OTHERWISE PURSUANT TO THIS  
7 SECTION OR PURSUANT TO COURT ORDER, OR UNLESS A GUARDIAN IS AUTHORIZED  
8 TO DECIDE ABOUT HEALTH CARE FOR THE ADULT PURSUANT TO ARTICLE EIGHTY-ONE  
9 OF THE MENTAL HYGIENE LAW.

10 2. DETERMINATION BY ATTENDING PHYSICIAN. A DETERMINATION THAT AN ADULT  
11 PATIENT LACKS DECISION-MAKING CAPACITY, AS WELL AS AN ASSESSMENT OF THE  
12 CAUSE AND EXTENT OF THE PATIENT'S INCAPACITY AND THE LIKELIHOOD THAT THE  
13 PATIENT WILL REGAIN DECISION-MAKING CAPACITY, SHALL BE MADE BY AN  
14 ATTENDING PHYSICIAN TO A REASONABLE DEGREE OF CERTAINTY.

15 3. INDEPENDENT DETERMINATIONS. (A) (I) IN A RESIDENTIAL HEALTH CARE  
16 FACILITY, A HEALTH OR SOCIAL SERVICES PRACTITIONER EMPLOYED BY OR OTHER-  
17 WISE FORMALLY AFFILIATED WITH THE FACILITY MUST INDEPENDENTLY DETERMINE  
18 WHETHER AN ADULT PATIENT LACKS DECISION-MAKING CAPACITY. IN A GENERAL  
19 HOSPITAL, A HEALTH OR SOCIAL SERVICES PRACTITIONER EMPLOYED BY OR OTHER-  
20 WISE FORMALLY AFFILIATED WITH THE FACILITY MUST INDEPENDENTLY DETERMINE  
21 WHETHER AN ADULT PATIENT LACKS DECISION-MAKING CAPACITY IF THE SURRO-  
22 GATE'S DECISION CONCERNS THE WITHDRAWAL OR WITHHOLDING OF LIFE-SUSTAIN-  
23 ING TREATMENT.

24 (II) IF AN ATTENDING PHYSICIAN HAS DETERMINED THAT THE PATIENT LACKS  
25 DECISION-MAKING CAPACITY AND THE HEALTH OR SOCIAL SERVICES PRACTITIONER  
26 CONSULTED FOR AN INDEPENDENT DETERMINATION DISAGREES WITH THE ATTENDING  
27 PHYSICIAN'S DETERMINATION, THE MATTER SHALL BE REFERRED TO THE ETHICS  
28 REVIEW COMMITTEE IF IT CANNOT OTHERWISE BE RESOLVED.

29 (B) IF AN ATTENDING PHYSICIAN DETERMINES THAT A PATIENT LACKS DECI-  
30 SION-MAKING CAPACITY BECAUSE OF MENTAL RETARDATION OR DEVELOPMENTAL  
31 DISABILITY, THE ATTENDING PHYSICIAN WHO MAKES THE DETERMINATION MUST  
32 HAVE, OR MUST CONSULT WITH A HEALTH OR SOCIAL SERVICES PRACTITIONER WHO  
33 HAS SPECIALIZED TRAINING OR EXPERIENCE IN DIAGNOSING OR TREATING MENTAL  
34 ILLNESS OR DEVELOPMENTAL DISABILITIES OF THE SAME OR SIMILAR NATURE.

35 (C) HOSPITALS SHALL ADOPT WRITTEN POLICIES IDENTIFYING THE TRAINING  
36 AND CREDENTIALS OF HEALTH OR SOCIAL SERVICES PRACTITIONERS QUALIFIED TO  
37 PROVIDE INDEPENDENT DETERMINATIONS OF INCAPACITY.

38 4. INFORMING THE PATIENT AND SURROGATE. NOTICE OF A DETERMINATION THAT  
39 A SURROGATE WILL MAKE HEALTH CARE DECISIONS BECAUSE THE ADULT PATIENT  
40 HAS BEEN DETERMINED TO LACK DECISION-MAKING CAPACITY SHALL PROMPTLY BE  
41 GIVEN:

42 (A) TO THE PATIENT, WHERE THERE IS ANY INDICATION OF THE PATIENT'S  
43 ABILITY TO COMPREHEND THE INFORMATION; AND

44 (B) TO AT LEAST ONE PERSON ON THE SURROGATE LIST HIGHEST IN ORDER OF  
45 PRIORITY LISTED WHEN PERSONS IN PRIOR CLASSES ARE NOT REASONABLY AVAIL-  
46 ABLE PURSUANT TO SUBDIVISION ONE OF SECTION TWENTY-NINE HUNDRED NINETY-  
47 FOUR-D OF THIS ARTICLE.

48 5. LIMITED PURPOSE OF DETERMINATION. A DETERMINATION MADE PURSUANT TO  
49 THIS SECTION THAT AN ADULT PATIENT LACKS DECISION-MAKING CAPACITY SHALL  
50 NOT BE CONSTRUED AS A FINDING THAT THE PATIENT LACKS CAPACITY FOR ANY  
51 OTHER PURPOSE.

52 6. PRIORITY OF PATIENT'S DECISION. NOTWITHSTANDING A DETERMINATION  
53 PURSUANT TO THIS SECTION THAT AN ADULT PATIENT LACKS DECISION-MAKING  
54 CAPACITY, IF THE PATIENT OBJECTS TO THE DETERMINATION OF INCAPACITY, OR  
55 TO THE CHOICE OF A SURROGATE OR TO A HEALTH CARE DECISION MADE BY A  
56 SURROGATE OR MADE PURSUANT TO SECTION TWENTY-NINE HUNDRED NINETY-FOUR-G

1 OF THIS ARTICLE, THE PATIENT'S OBJECTION OR DECISION SHALL PREVAIL  
2 UNLESS A COURT OF COMPETENT JURISDICTION HAS DETERMINED THAT THE PATIENT  
3 LACKS DECISION-MAKING CAPACITY OR THE PATIENT IS OR HAS BEEN ADJUDGED  
4 INCOMPETENT FOR ALL PURPOSES.

5 7. CONFIRMATION OF CONTINUED LACK OF DECISION-MAKING CAPACITY. AN  
6 ATTENDING PHYSICIAN SHALL CONFIRM THE ADULT PATIENT'S CONTINUED LACK OF  
7 DECISION-MAKING CAPACITY BEFORE COMPLYING WITH HEALTH CARE DECISIONS  
8 MADE PURSUANT TO THIS ARTICLE, OTHER THAN THOSE DECISIONS MADE AT OR  
9 ABOUT THE TIME OF THE INITIAL DETERMINATION. AN INDEPENDENT DETERMI-  
10 NATION OF THE PATIENT'S CONTINUED LACK OF DECISION-MAKING CAPACITY SHALL  
11 BE REQUIRED IF THE SUBSEQUENT HEALTH CARE DECISION CONCERNS THE WITH-  
12 HOLDING OR WITHDRAWAL OF LIFE-SUSTAINING TREATMENT. HEALTH CARE PROVID-  
13 ERS SHALL NOT BE REQUIRED TO INFORM THE PATIENT OR SURROGATE OF THE  
14 CONFIRMATION.

15 S 2994-D. HEALTH CARE DECISIONS FOR ADULT PATIENTS BY SURROGATES. 1.  
16 IDENTIFYING THE SURROGATE. ONE PERSON FROM THE FOLLOWING LIST, CHOSEN  
17 FROM THE CLASS HIGHEST IN PRIORITY WHEN PERSONS IN PRIOR CLASSES ARE NOT  
18 REASONABLY AVAILABLE, WILLING, AND COMPETENT TO ACT, SHALL BE THE SURRO-  
19 GATE FOR AN ADULT PATIENT WITHOUT DECISION-MAKING CAPACITY:

20 (A) A GUARDIAN AUTHORIZED TO DECIDE ABOUT HEALTH CARE PURSUANT TO  
21 ARTICLE EIGHTY-ONE OF THE MENTAL HYGIENE LAW;

22 (B) AN INDIVIDUAL, EIGHTEEN YEARS OF AGE OR OLDER, DESIGNATED ORALLY  
23 BY THE PATIENT TO SERVE AS SURROGATE, IF SUCH DESIGNATION WAS MADE IN  
24 THE PRESENCE OF TWO ADULT WITNESSES, EITHER OF WHOM MAY BE AN EMPLOYEE  
25 OF OR AFFILIATED WITH A FACILITY AT WHICH THE PATIENT IS RECEIVING  
26 TREATMENT, BUT NEITHER OF WHOM IS DESIGNATED AS THE SURROGATE UNDER THIS  
27 PARAGRAPH, AND THOSE WITNESSES AFFIRM THAT THE PATIENT REASONABLY  
28 APPEARED TO HAVE DECISION-MAKING CAPACITY TO MAKE SUCH A DESIGNATION;

29 (C) AN INDIVIDUAL, EIGHTEEN YEARS OF AGE OR OLDER, WHO IS A MEMBER OF  
30 ANY ONE OF THE CLASSES SET FORTH IN THIS SUBDIVISION AND WHO IS DESIG-  
31 NATED BY THE PERSON WHO OTHERWISE WOULD BE CHOSEN TO ACT AS SURROGATE  
32 BASED ON THE PRIORITY LIST ESTABLISHED IN THIS SUBDIVISION, PROVIDED  
33 THAT NO PERSON IN A CLASS HIGHER IN PRIORITY THAN THE PERSON DESIGNATED  
34 OBJECTS;

35 (D) THE SPOUSE, IF NOT LEGALLY SEPARATED FROM THE PATIENT, OR THE  
36 DOMESTIC PARTNER;

37 (E) A SON OR DAUGHTER EIGHTEEN YEARS OF AGE OR OLDER;

38 (F) A PARENT;

39 (G) A BROTHER OR SISTER EIGHTEEN YEARS OF AGE OR OLDER;

40 (H) A CLOSE RELATIVE OR CLOSE FRIEND.

41 2. RESTRICTIONS ON WHO MAY BE A SURROGATE. AN OPERATOR, ADMINISTRATOR,  
42 OR EMPLOYEE OF A HOSPITAL, A PHYSICIAN WHO HAS PRIVILEGES AT THE HOSPI-  
43 TAL OR A HEALTH CARE PROVIDER UNDER CONTRACT WITH THE HOSPITAL MAY NOT  
44 SERVE AS THE SURROGATE FOR ANY ADULT WHO IS A PATIENT OF SUCH HOSPITAL,  
45 UNLESS SUCH INDIVIDUAL IS RELATED TO THE PATIENT BY BLOOD, MARRIAGE, OR  
46 ADOPTION, OR IS A CLOSE FRIEND OF THE PATIENT WHOSE FRIENDSHIP WITH THE  
47 PATIENT PRECEDED THE PATIENT'S ADMISSION TO THE FACILITY. IF A PHYSICIAN  
48 SERVES AS SURROGATE, THE PHYSICIAN SHALL NOT ACT AS THE PATIENT'S  
49 ATTENDING PHYSICIAN AFTER HIS OR HER AUTHORITY AS SURROGATE BEGINS.

50 3. AUTHORITY AND DUTIES OF SURROGATE. (A) SCOPE OF SURROGATE'S AUTHOR-  
51 ITY.

52 (I) SUBJECT TO THE STANDARDS AND LIMITATIONS OF THIS ARTICLE, THE  
53 SURROGATE SHALL HAVE THE AUTHORITY TO MAKE ANY AND ALL HEALTH CARE DECI-  
54 SIONS ON THE ADULT PATIENT'S BEHALF THAT THE PATIENT COULD MAKE.

55 (II) NOTHING IN THIS ARTICLE SHALL OBLIGATE HEALTH CARE PROVIDERS TO  
56 SEEK THE CONSENT OF A SURROGATE IF AN ADULT PATIENT HAS ALREADY MADE A

1 DECISION ABOUT THE PROPOSED HEALTH CARE, EXPRESSED ORALLY OR IN WRITING,  
2 INCLUDING A DECISION ABOUT WITHDRAWING OR WITHHOLDING LIFE-SUSTAINING  
3 TREATMENT. IF AN ATTENDING PHYSICIAN RELIES ON THE PATIENT'S PRIOR DECI-  
4 SION, THE PHYSICIAN SHALL RECORD THE PRIOR DECISION IN THE PATIENT'S  
5 MEDICAL RECORD. IF A SURROGATE HAS ALREADY BEEN DESIGNATED FOR THE  
6 PATIENT, THE ATTENDING PHYSICIAN SHALL MAKE REASONABLE EFFORTS TO NOTIFY  
7 THE SURROGATE PRIOR TO IMPLEMENTING THE DECISION.

8 (B) COMMENCEMENT OF SURROGATE'S AUTHORITY. THE SURROGATE'S AUTHORITY  
9 SHALL COMMENCE UPON A DETERMINATION, MADE PURSUANT TO SECTION  
10 TWENTY-NINE HUNDRED NINETY-FOUR-C OF THIS ARTICLE, THAT THE ADULT  
11 PATIENT LACKS DECISION-MAKING CAPACITY. IN THE EVENT AN ATTENDING PHYSI-  
12 CIAN DETERMINES THAT THE PATIENT HAS REGAINED DECISION-MAKING CAPACITY,  
13 THE AUTHORITY OF THE SURROGATE SHALL CEASE.

14 (C) RIGHT AND DUTY TO BE INFORMED. NOTWITHSTANDING ANY LAW TO THE  
15 CONTRARY, THE SURROGATE SHALL HAVE THE RIGHT TO RECEIVE MEDICAL INFORMA-  
16 TION AND MEDICAL RECORDS NECESSARY TO MAKE INFORMED DECISIONS ABOUT THE  
17 PATIENT'S HEALTH CARE. HEALTH CARE PROVIDERS SHALL PROVIDE AND THE  
18 SURROGATE SHALL SEEK INFORMATION NECESSARY TO MAKE AN INFORMED DECISION,  
19 INCLUDING INFORMATION ABOUT THE PATIENT'S DIAGNOSIS, PROGNOSIS, THE  
20 NATURE AND CONSEQUENCES OF PROPOSED HEALTH CARE, AND THE BENEFITS AND  
21 RISKS OF AND ALTERNATIVE TO PROPOSED HEALTH CARE.

22 4. DECISION-MAKING STANDARDS. (A) THE SURROGATE SHALL MAKE HEALTH CARE  
23 DECISIONS:

24 (I) IN ACCORDANCE WITH THE PATIENT'S WISHES, INCLUDING THE PATIENT'S  
25 RELIGIOUS AND MORAL BELIEFS; OR

26 (II) IF THE PATIENT'S WISHES ARE NOT REASONABLY KNOWN AND CANNOT WITH  
27 REASONABLE DILIGENCE BE ASCERTAINED, IN ACCORDANCE WITH THE PATIENT'S  
28 BEST INTERESTS. AN ASSESSMENT OF THE PATIENT'S BEST INTERESTS SHALL  
29 INCLUDE: CONSIDERATION OF THE DIGNITY AND UNIQUENESS OF EVERY PERSON;  
30 THE POSSIBILITY AND EXTENT OF PRESERVING THE PATIENT'S LIFE; THE PRESER-  
31 VATION, IMPROVEMENT OR RESTORATION OF THE PATIENT'S HEALTH OR FUNCTION-  
32 ING; THE RELIEF OF THE PATIENT'S SUFFERING; AND ANY MEDICAL CONDITION  
33 AND SUCH OTHER CONCERNS AND VALUES AS A REASONABLE PERSON IN THE  
34 PATIENT'S CIRCUMSTANCES WOULD WISH TO CONSIDER.

35 (B) IN ALL CASES, THE SURROGATE'S ASSESSMENT OF THE PATIENT'S WISHES  
36 AND BEST INTERESTS SHALL BE PATIENT-CENTERED; HEALTH CARE DECISIONS  
37 SHALL BE MADE ON AN INDIVIDUALIZED BASIS FOR EACH PATIENT, AND SHALL BE  
38 CONSISTENT WITH THE VALUES OF THE PATIENT, INCLUDING THE PATIENT'S RELI-  
39 GIOUS AND MORAL BELIEFS, TO THE EXTENT REASONABLY POSSIBLE.

40 5. DECISIONS TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT. IN  
41 ADDITION TO THE STANDARDS SET FORTH IN SUBDIVISION FOUR OF THIS SECTION,  
42 DECISIONS BY SURROGATES TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREAT-  
43 MENT SHALL BE AUTHORIZED ONLY IF THE FOLLOWING CONDITIONS ARE SATISFIED,  
44 AS APPLICABLE:

45 (A) (I) TREATMENT WOULD BE AN EXTRAORDINARY BURDEN TO THE PATIENT AND  
46 AN ATTENDING PHYSICIAN DETERMINES, WITH THE INDEPENDENT CONCURRENCE OF  
47 ANOTHER PHYSICIAN, THAT, TO A REASONABLE DEGREE OF MEDICAL CERTAINTY AND  
48 IN ACCORD WITH ACCEPTED MEDICAL STANDARDS, (A) THE PATIENT HAS AN  
49 ILLNESS OR INJURY WHICH CAN BE EXPECTED TO CAUSE DEATH WITHIN SIX  
50 MONTHS, WHETHER OR NOT TREATMENT IS PROVIDED; OR (B) THE PATIENT IS  
51 PERMANENTLY UNCONSCIOUS; OR

52 (II) THE PROVISION OF TREATMENT WOULD INVOLVE SUCH PAIN, SUFFERING OR  
53 OTHER BURDEN THAT IT WOULD REASONABLY BE DEEMED INHUMANE OR EXTRAOR-  
54 DINARILY BURDENSOME UNDER THE CIRCUMSTANCES AND THE PATIENT HAS AN IRRE-  
55 VERSIBLE OR INCURABLE CONDITION, AS DETERMINED BY AN ATTENDING PHYSICIAN  
56 WITH THE INDEPENDENT CONCURRENCE OF ANOTHER PHYSICIAN TO A REASONABLE

1 DEGREE OF MEDICAL CERTAINTY AND IN ACCORD WITH ACCEPTED MEDICAL STAND-  
2 ARDS.

3 (B) IN A RESIDENTIAL HEALTH CARE FACILITY, A SURROGATE SHALL HAVE THE  
4 AUTHORITY TO REFUSE LIFE-SUSTAINING TREATMENT UNDER SUBPARAGRAPH (II) OF  
5 PARAGRAPH (A) OF THIS SUBDIVISION ONLY IF THE ETHICS REVIEW COMMITTEE,  
6 INCLUDING AT LEAST ONE PHYSICIAN WHO IS NOT DIRECTLY RESPONSIBLE FOR THE  
7 PATIENT'S CARE, OR A COURT OF COMPETENT JURISDICTION, REVIEWS THE DECI-  
8 SION AND DETERMINES THAT IT MEETS THE STANDARDS SET FORTH IN THIS ARTI-  
9 CLE. THIS REQUIREMENT SHALL NOT APPLY TO A DECISION TO WITHHOLD CARDIOP-  
10 ULMONARY RESUSCITATION.

11 (C) IN A GENERAL HOSPITAL, AS DEFINED IN SUBDIVISION TEN OF SECTION  
12 TWENTY-EIGHT HUNDRED ONE OF THIS CHAPTER, IF THE ATTENDING PHYSICIAN  
13 OBJECTS TO A SURROGATE'S DECISION, UNDER SUBPARAGRAPH (II) OF PARAGRAPH  
14 (A) OF THIS SUBDIVISION, TO WITHDRAW OR WITHHOLD NUTRITION AND HYDRATION  
15 PROVIDED BY MEANS OF MEDICAL TREATMENT THE DECISION SHALL NOT BE IMPLE-  
16 MENTED UNTIL THE ETHICS REVIEW COMMITTEE, INCLUDING AT LEAST ONE PHYSI-  
17 CIAN WHO IS NOT DIRECTLY RESPONSIBLE FOR THE PATIENT'S CARE, OR A COURT  
18 OF COMPETENT JURISDICTION, REVIEWS THE DECISION AND DETERMINES THAT IT  
19 MEETS THE STANDARDS SET FORTH IN THIS SUBDIVISION AND SUBDIVISION FOUR  
20 OF THIS SECTION.

21 (D) PROVIDING NUTRITION AND HYDRATION ORALLY, WITHOUT RELIANCE ON  
22 MEDICAL TREATMENT, IS NOT HEALTH CARE UNDER THIS ARTICLE AND IS NOT  
23 SUBJECT TO THIS ARTICLE.

24 (E) EXPRESSION OF DECISIONS. THE SURROGATE SHALL EXPRESS A DECISION TO  
25 WITHDRAW OR WITHHOLD LIFE-SUSTAINING TREATMENT EITHER ORALLY OR IN WRIT-  
26 ING.

27 6. DECISIONS RELATING TO PATIENTS WITH MENTAL RETARDATION. (A) THIS  
28 SUBDIVISION APPLIES TO DECISIONS RELATING TO WITHHOLDING OR WITHDRAWING  
29 LIFE-SUSTAINING TREATMENT FOR PATIENTS WHO LACK CAPACITY BECAUSE OF  
30 MENTAL RETARDATION, AS DEFINED IN SECTION 1.03 OF THE MENTAL HYGIENE  
31 LAW, OR AN IMPAIRMENT OF GENERAL INTELLECTUAL FUNCTIONING OR ADAPTIVE  
32 BEHAVIOR THAT MEETS THAT DEFINITION.

33 (B) SUCH DECISION SHALL BE MADE UNDER THIS ARTICLE BY A SURROGATE, OR  
34 IN THE CASE OF A MINOR, BY A PARENT OR GUARDIAN, PROVIDED THAT:

35 (I) SUCH DECISION IS NOT BASED ON A PRESUMPTION THAT PERSONS WITH  
36 MENTAL RETARDATION OR SIMILAR IMPAIRMENTS ARE NOT ENTITLED TO EQUAL  
37 RIGHTS, EQUAL PROTECTION, RESPECT, FULL AND EFFICACIOUS HEALTH CARE AND  
38 DIGNITY AFFORDED TO PERSONS WITHOUT MENTAL RETARDATION OR OTHER SIMILAR  
39 IMPAIRMENTS;

40 (II) SUCH DECISION IS IMPLEMENTED AFTER ALL OTHER TREATMENT OPTIONS  
41 WHICH WOULD HAVE BEEN CONSIDERED FOR A PATIENT WITHOUT MENTAL RETARDA-  
42 TION OR A SIMILAR IMPAIRMENT HAVE BEEN CONSIDERED;

43 (III) THE DETERMINATION AND CONFIRMATION OF THE PATIENT'S INCAPACITY  
44 PURSUANT TO SECTION TWENTY-NINE HUNDRED NINETY-FOUR-C OF THIS ARTICLE  
45 AND A DECISION TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT, IF  
46 ANY, ARE DOCUMENTED AND ENTERED ON THE PATIENT'S HEALTH CARE RECORD; AND

47 (IV) AT LEAST FORTY-EIGHT HOURS OR AS SOON AS PRACTICABLE PRIOR TO  
48 IMPLEMENTATION OF A DECISION TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING  
49 TREATMENT, THE ATTENDING PHYSICIAN SHALL NOTIFY THE PATIENT, WHERE THERE  
50 IS ANY INDICATION OF THE PATIENT'S ABILITY TO COMPREHEND THE INFORMA-  
51 TION, AND, IF THE PATIENT RESIDES IN A RESIDENTIAL SETTING CERTIFIED OR  
52 LICENSED BY THE COMMISSIONER OF THE OFFICE OF MENTAL RETARDATION AND  
53 DEVELOPMENTAL DISABILITIES, SUCH COMMISSIONER OR HIS OR HER DESIGNEE.  
54 THE COMMISSIONER OF THE OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL  
55 DISABILITIES, AT HIS OR HER DISCRETION, MAY NOTIFY THE MENTAL HYGIENE

1 LEGAL SERVICES. IN ADDITION, THE HOSPITAL SHALL COMPLY WITH THE NOTICE  
2 REQUIREMENTS UNDER THIS SECTION.

3 (C) (I) IN THE EVENT OF AN OBJECTION UNDER THIS ARTICLE, BY A PERSON  
4 CONNECTED WITH THE CASE, TO A DECISION UNDER THIS SUBDIVISION TO WITH-  
5 HOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT SUCH DECISION SHALL BE  
6 SUSPENDED PENDING REVIEW BY THE ETHICS REVIEW COMMITTEE.

7 (II) A PHYSICIAN WHO RECEIVES AN ORDER TO IMPLEMENT A DECISION UNDER  
8 THIS SUBDIVISION TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING CARE AND  
9 OBJECTS TO SUCH ORDER, SHALL PROMPTLY REFER SUCH MATTER TO THE ETHICS  
10 REVIEW COMMITTEE, PURSUANT TO SUBDIVISION ONE OF SECTION TWENTY-NINE  
11 HUNDRED NINETY-FOUR-F OF THIS ARTICLE.

12 (III) FOR ADULTS UNDER THIS SUBDIVISION WITHOUT A SURROGATE WILLING OR  
13 ABLE TO ACT UNDER THIS ARTICLE, A SURROGATE DECISION MAKING COMMITTEE,  
14 UNDER ARTICLE EIGHTY OF THE MENTAL HYGIENE LAW, SHALL BE AUTHORIZED TO  
15 MAKE A DECISION UNDER THIS SUBDIVISION TO WITHHOLD OR WITHDRAW LIFE-SUS-  
16 TAINING TREATMENT.

17 (IV) A SURROGATE ACTING UNDER THIS SUBDIVISION, OR IN THE CASE OF A  
18 MINOR, A PARENT OR GUARDIAN, SHALL HAVE THE AFFIRMATIVE OBLIGATION TO  
19 ADVOCATE FOR FULL AND EFFICACIOUS CARE FOR THE PATIENT, SUBJECT TO AND  
20 CONSISTENT WITH SURROGATE'S DECISION-MAKING AUTHORITY UNDER THIS ARTI-  
21 CLE.

22 (V) NOTHING IN THIS SUBDIVISION SHALL IMPOSE AN OBLIGATION ON AN  
23 ATTENDING PHYSICIAN TO EVALUATE A PATIENT FOR MENTAL RETARDATION, AS  
24 DEFINED IN SECTION 1.03 OF THE MENTAL HYGIENE LAW, OR A SIMILAR IMPAIR-  
25 MENT OF GENERAL INTELLECTUAL FUNCTIONING OR ADAPTIVE BEHAVIOR UNLESS IT  
26 IS READILY APPARENT THAT THE PATIENT IS A PERSON WITH MENTAL RETARDATION  
27 OR A SIMILAR INTELLECTUAL OR ADAPTIVE IMPAIRMENT OR THE PATIENT IS IDEN-  
28 TIFIED AS SUCH PERSON.

29 S 2994-E. DECISIONS ABOUT LIFE-SUSTAINING TREATMENT FOR MINOR  
30 PATIENTS. 1. AUTHORITY OF PARENT OR GUARDIAN. THE PARENT OR GUARDIAN OF  
31 A MINOR PATIENT SHALL HAVE THE AUTHORITY TO MAKE DECISIONS ABOUT  
32 LIFE-SUSTAINING TREATMENT, INCLUDING DECISIONS TO WITHHOLD OR WITHDRAW  
33 SUCH TREATMENT, SUBJECT TO THE PROVISIONS OF THIS SECTION AND SUBDIVI-  
34 SION FIVE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE.

35 2. DECISION-MAKING STANDARDS AND PROCEDURES FOR MINOR PATIENT. (A) THE  
36 PARENT OR GUARDIAN OF A MINOR PATIENT SHALL MAKE DECISIONS IN ACCORDANCE  
37 WITH THE MINOR'S BEST INTERESTS, CONSISTENT WITH THE STANDARDS SET FORTH  
38 IN SUBDIVISION FOUR OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS  
39 ARTICLE, TAKING INTO ACCOUNT THE MINOR'S WISHES AS APPROPRIATE UNDER THE  
40 CIRCUMSTANCES.

41 (B) AN ATTENDING PHYSICIAN, IN CONSULTATION WITH A MINOR'S PARENT OR  
42 GUARDIAN, SHALL DETERMINE WHETHER A MINOR PATIENT HAS DECISION-MAKING  
43 CAPACITY FOR A DECISION TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREAT-  
44 MENT. IF THE MINOR HAS SUCH CAPACITY, A PARENT'S OR GUARDIAN'S DECISION  
45 TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT FOR THE MINOR MAY NOT  
46 BE IMPLEMENTED WITHOUT THE MINOR'S CONSENT.

47 (C) WHERE A PARENT OR GUARDIAN OF A MINOR PATIENT HAS MADE A DECISION  
48 TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT AND AN ATTENDING  
49 PHYSICIAN HAS REASON TO BELIEVE THAT THE MINOR PATIENT HAS A PARENT OR  
50 GUARDIAN WHO HAS NOT BEEN INFORMED OF THE DECISION, INCLUDING A NON-CUS-  
51 TODIAL PARENT OR GUARDIAN, AN ATTENDING PHYSICIAN OR SOMEONE ACTING ON  
52 HIS OR HER BEHALF, SHALL MAKE REASONABLE EFFORTS TO DETERMINE IF THE  
53 UNINFORMED PARENT OR GUARDIAN HAS MAINTAINED SUBSTANTIAL AND CONTINUOUS  
54 CONTACT WITH THE MINOR AND, IF SO, SHALL MAKE DILIGENT EFFORTS TO NOTIFY  
55 THAT PARENT OR GUARDIAN PRIOR TO IMPLEMENTING THE DECISION.

1 3. DECISION-MAKING STANDARDS AND PROCEDURES FOR EMANCIPATED MINOR  
2 PATIENT. (A) IF AN ATTENDING PHYSICIAN DETERMINES THAT A PATIENT IS AN  
3 EMANCIPATED MINOR PATIENT WITH DECISION-MAKING CAPACITY, THE PATIENT  
4 SHALL HAVE THE AUTHORITY TO DECIDE ABOUT LIFE-SUSTAINING TREATMENT. SUCH  
5 AUTHORITY SHALL INCLUDE A DECISION TO WITHHOLD OR WITHDRAW LIFE-SUSTAIN-  
6 ING TREATMENT IF AN ATTENDING PHYSICIAN AND THE ETHICS REVIEW COMMITTEE  
7 DETERMINE THAT THE DECISION ACCORDS WITH THE STANDARDS FOR SURROGATE  
8 DECISIONS FOR ADULTS, AND THE ETHICS REVIEW COMMITTEE APPROVES THE DECI-  
9 SION.

10 (B) IF THE HOSPITAL CAN READILY ASCERTAIN THE IDENTITY OF THE PARENTS  
11 OR GUARDIAN OF AN EMANCIPATED MINOR PATIENT, THE HOSPITAL SHALL NOTIFY  
12 SUCH PERSONS PRIOR TO WITHHOLDING OR WITHDRAWING LIFE-SUSTAINING TREAT-  
13 MENT PURSUANT TO THIS SUBDIVISION.

14 S 2994-F. OBLIGATIONS OF ATTENDING PHYSICIAN. 1. AN ATTENDING PHYSI-  
15 CIAN INFORMED OF A DECISION TO WITHDRAW OR WITHHOLD LIFE-SUSTAINING  
16 TREATMENT MADE PURSUANT TO THE STANDARDS OF THIS ARTICLE SHALL RECORD  
17 THE DECISION IN THE PATIENT'S MEDICAL RECORD, REVIEW THE MEDICAL BASIS  
18 FOR THE DECISION, AND SHALL EITHER: (A) IMPLEMENT THE DECISION, OR (B)  
19 PROMPTLY MAKE HIS OR HER OBJECTION TO THE DECISION AND THE REASONS FOR  
20 THE OBJECTION KNOWN TO THE DECISION-MAKER, AND EITHER MAKE ALL REASON-  
21 ABLE EFFORTS TO ARRANGE FOR THE TRANSFER OF THE PATIENT TO ANOTHER  
22 PHYSICIAN, IF NECESSARY, OR PROMPTLY REFER THE MATTER TO THE ETHICS  
23 REVIEW COMMITTEE.

24 2. IF AN ATTENDING PHYSICIAN HAS ACTUAL NOTICE OF THE FOLLOWING  
25 OBJECTIONS OR DISAGREEMENTS, HE OR SHE SHALL PROMPTLY REFER THE MATTER  
26 TO THE ETHICS REVIEW COMMITTEE IF THE OBJECTION OR DISAGREEMENT CANNOT  
27 OTHERWISE BE RESOLVED:

28 (A) A HEALTH OR SOCIAL SERVICES PRACTITIONER CONSULTED FOR AN INDE-  
29 PENDENT DETERMINATION THAT AN ADULT PATIENT LACKS DECISION-MAKING CAPAC-  
30 ITY DISAGREES WITH THE ATTENDING PHYSICIAN'S DETERMINATION;

31 (B) ANY PERSON ON THE SURROGATE LIST OF THE PATIENT OBJECTS TO THE  
32 DESIGNATION OF THE SURROGATE PURSUANT TO SUBDIVISION ONE OF SECTION  
33 TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE; OR

34 (C) ANY PERSON ON THE SURROGATE LIST OF THE PATIENT OBJECTS TO A  
35 SURROGATE'S DECISION; OR

36 (D) A PARENT OR GUARDIAN OF A MINOR PATIENT OBJECTS TO THE DECISION BY  
37 ANOTHER PARENT OR GUARDIAN OF THE MINOR; OR

38 (E) A MINOR PATIENT REFUSES LIFE-SUSTAINING TREATMENT, AND THE MINOR'S  
39 PARENT OR GUARDIAN WISHES THE TREATMENT TO BE PROVIDED, OR THE MINOR  
40 PATIENT OBJECTS TO AN ATTENDING PHYSICIAN'S DETERMINATION ABOUT DECI-  
41 SION-MAKING CAPACITY OR RECOMMENDATION ABOUT LIFE-SUSTAINING TREATMENT.

42 3. NOTWITHSTANDING THE PROVISIONS OF THIS SECTION OR SUBDIVISION ONE  
43 OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-Q OF THIS ARTICLE, IF A  
44 SURROGATE DIRECTS THE PROVISION OF LIFE-SUSTAINING TREATMENT, THE DENIAL  
45 OF WHICH IN REASONABLE MEDICAL JUDGMENT WOULD BE LIKELY TO RESULT IN THE  
46 DEATH OF THE PATIENT, A HOSPITAL OR INDIVIDUAL HEALTH CARE PROVIDER THAT  
47 DOES NOT WISH TO PROVIDE SUCH TREATMENT SHALL NONETHELESS COMPLY WITH  
48 THE SURROGATE'S DECISION PENDING EITHER TRANSFER OF THE PATIENT TO A  
49 WILLING HOSPITAL OR INDIVIDUAL HEALTH CARE PROVIDER, OR JUDICIAL REVIEW  
50 IN ACCORDANCE WITH SECTION TWENTY-NINE HUNDRED NINETY-FOUR-R OF THIS  
51 ARTICLE.

52 S 2994-G. HEALTH CARE DECISIONS FOR ADULT PATIENTS WITHOUT SURROGATES.

53 1. IDENTIFYING ADULT PATIENTS WITHOUT SURROGATES. WITHIN A REASONABLE  
54 TIME AFTER ADMISSION AS AN INPATIENT TO THE HOSPITAL OF EACH ADULT  
55 PATIENT, THE HOSPITAL SHALL MAKE REASONABLE EFFORTS TO DETERMINE IF THE  
56 PATIENT HAS APPOINTED A HEALTH CARE AGENT OR IF AT LEAST ONE INDIVIDUAL

1 IS AVAILABLE TO SERVE AS THE PATIENT'S SURROGATE IN THE EVENT THE  
2 PATIENT LOSES DECISION-MAKING CAPACITY. IF NO SUCH POTENTIAL SURROGATE  
3 IS IDENTIFIED, THE HOSPITAL SHALL IDENTIFY, TO THE EXTENT REASONABLY  
4 POSSIBLE, THE PATIENT'S WISHES AND PREFERENCES, INCLUDING THE PATIENT'S  
5 RELIGIOUS AND MORAL BELIEFS, ABOUT PENDING HEALTH CARE DECISIONS, AND  
6 SHALL RECORD ITS FINDINGS IN THE PATIENT'S MEDICAL RECORD.

7 2. DECISION-MAKING STANDARDS AND PROCEDURES. ANY HEALTH CARE DECISION  
8 MADE PURSUANT TO THIS SECTION SHALL BE MADE IN ACCORDANCE WITH THE STAN-  
9 DARDS SET FORTH IN SUBDIVISION FOUR OF SECTION TWENTY-NINE HUNDRED NINE-  
10 TY-FOUR-D OF THIS ARTICLE AND SHALL NOT BE BASED ON THE FINANCIAL INTER-  
11 ESTS OF THE HOSPITAL OR ANY OTHER HEALTH CARE PROVIDER. THE PROCEDURES  
12 FOR MAKING HEALTH CARE DECISIONS FOR ADULT PATIENTS WITHOUT SURROGATES  
13 ARE SPECIFIED IN THE FOLLOWING SUBDIVISIONS. THE SPECIFIC PROCEDURES TO  
14 BE FOLLOWED DEPEND ON WHETHER THE DECISION INVOLVES ROUTINE MEDICAL  
15 TREATMENT, MAJOR MEDICAL TREATMENT, OR THE WITHHOLDING OR WITHDRAWAL OF  
16 LIFE-SUSTAINING TREATMENT. IN ADDITION, CERTAIN ASPECTS OF THESE PROCE-  
17 DURES DEPEND ON WHETHER THE PATIENT IS IN A GENERAL HOSPITAL OR A RESI-  
18 DENTIAL HEALTH CARE FACILITY.

19 3. ROUTINE MEDICAL TREATMENT. (A) FOR PURPOSES OF THIS SUBDIVISION,  
20 "ROUTINE MEDICAL TREATMENT" MEANS ANY TREATMENT, SERVICE, OR PROCEDURE  
21 TO DIAGNOSE OR TREAT AN INDIVIDUAL'S PHYSICAL OR MENTAL CONDITION, SUCH  
22 AS THE ADMINISTRATION OF MEDICATION, THE EXTRACTION OF BODILY FLUIDS FOR  
23 ANALYSIS, OR DENTAL CARE PERFORMED WITH A LOCAL ANESTHETIC, FOR WHICH  
24 HEALTH CARE PROVIDERS ORDINARILY DO NOT SEEK SPECIFIC CONSENT FROM THE  
25 PATIENT OR AUTHORIZED REPRESENTATIVE. IT SHALL NOT INCLUDE THE LONG-TERM  
26 PROVISION OF TREATMENT SUCH AS VENTILATOR SUPPORT OR A NASOGASTRIC TUBE  
27 BUT SHALL INCLUDE SUCH TREATMENT WHEN PROVIDED AS PART OF POST-OPERATIVE  
28 CARE OR IN RESPONSE TO AN ACUTE ILLNESS AND RECOVERY IS REASONABLY  
29 EXPECTED WITHIN ONE MONTH OR LESS.

30 (B) IF NO SURROGATE IS REASONABLY AVAILABLE, WILLING, AND COMPETENT TO  
31 ACT, AN ATTENDING PHYSICIAN SHALL BE AUTHORIZED TO DECIDE ABOUT ROUTINE  
32 MEDICAL TREATMENT FOR AN ADULT PATIENT WHO HAS BEEN DETERMINED TO LACK  
33 DECISION-MAKING CAPACITY PURSUANT TO SECTION TWENTY-NINE HUNDRED NINE-  
34 TY-FOUR-C OF THIS ARTICLE. NOTHING IN THIS SUBDIVISION SHALL REQUIRE  
35 HEALTH CARE PROVIDERS TO OBTAIN SPECIFIC CONSENT FOR TREATMENT WHERE  
36 SPECIFIC CONSENT IS NOT OTHERWISE REQUIRED BY LAW.

37 4. MAJOR MEDICAL TREATMENT. (A) FOR PURPOSES OF THIS SUBDIVISION,  
38 "MAJOR MEDICAL TREATMENT" MEANS ANY TREATMENT, SERVICE OR PROCEDURE TO  
39 DIAGNOSE OR TREAT AN INDIVIDUAL'S PHYSICAL OR MENTAL CONDITION: (I)  
40 WHERE GENERAL ANESTHETIC IS USED; OR (II) WHICH INVOLVES ANY SIGNIFICANT  
41 RISK; OR (III) WHICH INVOLVES ANY SIGNIFICANT INVASION OF BODILY INTEG-  
42 RITY REQUIRING AN INCISION, PRODUCING SUBSTANTIAL PAIN, DISCOMFORT,  
43 DEBILITATION OR HAVING A SIGNIFICANT RECOVERY PERIOD; OR (IV) WHICH  
44 INVOLVES THE USE OF PHYSICAL RESTRAINTS, AS SPECIFIED IN REGULATIONS  
45 PROMULGATED BY THE COMMISSIONER, EXCEPT IN AN EMERGENCY; OR (V) WHICH  
46 INVOLVES THE USE OF PSYCHOACTIVE MEDICATIONS, EXCEPT WHEN PROVIDED AS  
47 PART OF POST-OPERATIVE CARE OR IN RESPONSE TO AN ACUTE ILLNESS AND  
48 TREATMENT IS REASONABLY EXPECTED TO BE ADMINISTERED OVER A PERIOD OF  
49 FORTY-EIGHT HOURS OR LESS, OR WHEN PROVIDED IN AN EMERGENCY.

50 (B) IF NO SURROGATE IS REASONABLY AVAILABLE, WILLING, AND COMPETENT TO  
51 ACT, A DECISION TO PROVIDE MAJOR MEDICAL TREATMENT, MADE IN ACCORDANCE  
52 WITH THE FOLLOWING REQUIREMENTS, SHALL BE AUTHORIZED FOR AN ADULT  
53 PATIENT WHO HAS BEEN DETERMINED TO LACK DECISION-MAKING CAPACITY PURSU-  
54 ANT TO SECTION TWENTY-NINE HUNDRED NINETY-FOUR-C OF THIS ARTICLE.

55 (I) AN ATTENDING PHYSICIAN SHALL MAKE A RECOMMENDATION IN CONSULTATION  
56 WITH HOSPITAL STAFF DIRECTLY RESPONSIBLE FOR THE PATIENT'S CARE.

1 (II) IN A GENERAL HOSPITAL, AT LEAST ONE OTHER PHYSICIAN DESIGNATED BY  
2 THE HOSPITAL MUST INDEPENDENTLY DETERMINE THAT THE RECOMMENDATION IS  
3 APPROPRIATE.

4 (III) IN A RESIDENTIAL HEALTH CARE FACILITY, THE MEDICAL DIRECTOR OF  
5 THE FACILITY, OR A PHYSICIAN DESIGNATED BY THE MEDICAL DIRECTOR, MUST  
6 INDEPENDENTLY DETERMINE THAT THE RECOMMENDATION IS APPROPRIATE; PROVIDED  
7 THAT IF THE MEDICAL DIRECTOR IS THE PATIENT'S ATTENDING PHYSICIAN, A  
8 DIFFERENT PHYSICIAN DESIGNATED BY THE RESIDENTIAL HEALTH CARE FACILITY  
9 MUST MAKE THIS INDEPENDENT DETERMINATION. ANY HEALTH OR SOCIAL SERVICES  
10 PRACTITIONER EMPLOYED BY OR OTHERWISE FORMALLY AFFILIATED WITH THE  
11 FACILITY MAY PROVIDE A SECOND OPINION FOR DECISIONS ABOUT PHYSICAL  
12 RESTRAINTS MADE PURSUANT TO THIS SUBDIVISION.

13 5. DECISIONS TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT. (A) IF  
14 NO SURROGATE IS REASONABLY AVAILABLE, WILLING, AND COMPETENT TO ACT, A  
15 COURT OF COMPETENT JURISDICTION MAY MAKE A DECISION TO WITHHOLD OR WITH-  
16 DRAW LIFE-SUSTAINING TREATMENT FOR AN ADULT PATIENT WHO HAS BEEN DETER-  
17 MINED TO LACK DECISION-MAKING CAPACITY PURSUANT TO SECTION TWENTY-NINE  
18 HUNDRED NINETY-FOUR-C OF THIS ARTICLE IF THE COURT FINDS THAT THE DECI-  
19 SION ACCORDS WITH STANDARDS FOR DECISIONS FOR ADULTS SET FORTH IN SUBDI-  
20 VISIONS FOUR AND FIVE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF  
21 THIS ARTICLE.

22 (B) IF NO SURROGATE IS REASONABLY AVAILABLE, WILLING AND COMPETENT TO  
23 ACT, AND THE ATTENDING PHYSICIAN, WITH INDEPENDENT CONCURRENCE OF A  
24 SECOND PHYSICIAN DESIGNATED BY THE HOSPITAL, DETERMINES TO A REASONABLE  
25 DEGREE OF MEDICAL CERTAINTY THAT:

26 (I) LIFE-SUSTAINING TREATMENT OFFERS THE PATIENT NO MEDICAL BENEFIT  
27 BECAUSE THE PATIENT WILL DIE IMMINENTLY, EVEN IF THE TREATMENT IS  
28 PROVIDED; AND

29 (II) THE PROVISION OF LIFE-SUSTAINING TREATMENT WOULD VIOLATE ACCEPTED  
30 MEDICAL STANDARDS, SUCH TREATMENT MAY BE WITHDRAWN OR WITHHELD FROM AN  
31 ADULT PATIENT WHO HAS BEEN DETERMINED TO LACK DECISION-MAKING CAPACITY  
32 PURSUANT TO SECTION TWENTY-NINE HUNDRED NINETY-FOUR-C OF THIS ARTICLE,  
33 WITHOUT JUDICIAL APPROVAL. THIS SUBDIVISION SHALL NOT APPLY TO ANY  
34 TREATMENT NECESSARY TO ALLEVIATE PAIN OR DISCOMFORT.

35 6. PHYSICIAN OBJECTION. IF A PHYSICIAN CONSULTED FOR A CONCURRING  
36 OPINION OBJECTS TO AN ATTENDING PHYSICIAN'S RECOMMENDATION OR DETERMI-  
37 NATION MADE PURSUANT TO THIS SECTION, OR A MEMBER OF THE HOSPITAL STAFF  
38 DIRECTLY RESPONSIBLE FOR THE PATIENT'S CARE OBJECTS TO AN ATTENDING  
39 PHYSICIAN'S RECOMMENDATION ABOUT MAJOR MEDICAL TREATMENT OR TREATMENT  
40 WITHOUT MEDICAL BENEFIT, THE MATTER SHALL BE REFERRED TO THE ETHICS  
41 REVIEW COMMITTEE IF IT CANNOT BE OTHERWISE RESOLVED.

42 S 2994-H. DECISIONS FOR PATIENTS TRANSFERRED FROM A MENTAL HYGIENE  
43 FACILITY. 1. IF A PATIENT IS TRANSFERRED FROM A MENTAL HYGIENE FACILITY  
44 TO A HOSPITAL, OTHER THAN A RESIDENTIAL CARE FACILITY, THE HOSPITAL  
45 SHALL NOTIFY THE FACILITY DIRECTOR OR THE MENTAL HEALTH REGIONAL DIREC-  
46 TOR WHEN:

47 (A) A DECISION IS MADE, PURSUANT TO SUBDIVISION FOUR OF SECTION TWEN-  
48 TY-NINE HUNDRED NINETY-FOUR-G OF THIS ARTICLE, REGARDING MAJOR MEDICAL  
49 TREATMENT FOR AN ADULT WITHOUT A SURROGATE; OR

50 (B) A SURROGATE OR A PARENT OF A MINOR CHILD CONSENTS TO WITHHOLD OR  
51 WITHDRAW LIFE-SUSTAINING TREATMENT FOR THE PATIENT PURSUANT TO THIS  
52 ARTICLE. A MENTAL HYGIENE FACILITY DIRECTOR WHO RECEIVES NOTICES PURSU-  
53 ANT TO THIS SUBDIVISION SHALL PROMPTLY CONVEY SUCH NOTICES TO THE MENTAL  
54 HYGIENE LEGAL SERVICE.

55 2. NOTHING IN THIS ARTICLE SHALL AFFECT OR DIMINISH THE AUTHORITY OF A  
56 SURROGATE DECISION-MAKING PANEL CONVENED TO DECIDE ABOUT MAJOR MEDICAL

1 TREATMENT PURSUANT TO ARTICLE EIGHTY OF THE MENTAL HYGIENE LAW. HEALTH  
2 CARE PROVIDERS MAY SEEK AUTHORIZATION FOR MAJOR MEDICAL TREATMENT FOR A  
3 PATIENT TRANSFERRED FROM A MENTAL HYGIENE FACILITY WHO HAS NO SURROGATE  
4 BY COMMENCING THE PROCESS SET FORTH IN SECTION TWENTY-NINE HUNDRED NINE-  
5 TY-FOUR-G OF THIS ARTICLE, OR BY COMMENCING A PROCEEDING PURSUANT TO  
6 ARTICLE EIGHTY OF THE MENTAL HYGIENE LAW IN ANY COUNTY WHERE SUCH FACIL-  
7 ITY IS OPERATING. IF A PROCEEDING PURSUANT TO ARTICLE EIGHTY OF THE  
8 MENTAL HYGIENE LAW IS COMMENCED, THE DECISION AND ALL SUBSEQUENT DECI-  
9 SIONS RELATED TO THE MAJOR MEDICAL TREATMENT PROPOSED IN THE INITIAL  
10 ARTICLE EIGHTY PROCEEDING SHALL BE MADE PURSUANT TO SUCH ARTICLE, UNLESS  
11 THE DECISION MUST BE EXPEDITED TO MEET THE PATIENT'S MEDICAL NEEDS.

12 S 2994-I. SPECIFIC POLICIES FOR ORDERS NOT TO RESUSCITATE. AN ORDER  
13 NOT TO RESUSCITATE SHALL BE WRITTEN IN THE PATIENT'S MEDICAL RECORD.  
14 CONSENT TO AN ORDER NOT TO RESUSCITATE SHALL NOT CONSTITUTE CONSENT TO  
15 WITHHOLD OR WITHDRAW TREATMENT OTHER THAN CARDIOPULMONARY RESUSCITATION.

16 S 2994-J. REVOCATION OF CONSENT. 1. A PATIENT, SURROGATE, OR PARENT OR  
17 GUARDIAN OF A MINOR PATIENT MAY AT ANY TIME REVOKE HIS OR HER CONSENT TO  
18 WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT BY INFORMING AN ATTENDING  
19 PHYSICIAN OR A MEMBER OF THE MEDICAL OR NURSING STAFF OF THE REVOCATION.

20 2. AN ATTENDING PHYSICIAN INFORMED OF A REVOCATION OF CONSENT MADE  
21 PURSUANT TO THIS SECTION SHALL IMMEDIATELY:

22 (A) RECORD THE REVOCATION IN THE PATIENT'S MEDICAL RECORD;

23 (B) CANCEL ANY ORDERS IMPLEMENTING THE DECISION TO WITHHOLD OR WITH-  
24 DRAW TREATMENT; AND

25 (C) NOTIFY THE HOSPITAL STAFF DIRECTLY RESPONSIBLE FOR THE PATIENT'S  
26 CARE OF THE REVOCATION AND ANY CANCELLATIONS.

27 3. ANY MEMBER OF THE MEDICAL OR NURSING STAFF INFORMED OF A REVOCATION  
28 MADE PURSUANT TO THIS SECTION SHALL IMMEDIATELY NOTIFY AN ATTENDING  
29 PHYSICIAN OF THE REVOCATION.

30 S 2994-K. IMPLEMENTATION AND REVIEW OF DECISIONS. 1. HOSPITALS SHALL  
31 ADOPT WRITTEN POLICIES REQUIRING IMPLEMENTATION AND REGULAR REVIEW OF  
32 DECISIONS TO WITHHOLD OR WITHDREW LIFE-SUSTAINING TREATMENT IN ACCORD-  
33 ANCE WITH ACCEPTED MEDICAL STANDARDS. HOSPITALS SHALL ALSO DEVELOP POLI-  
34 CIES IN ACCORD WITH ACCEPTED MEDICAL STANDARDS REGARDING DOCUMENTATION  
35 OF CLINICAL DETERMINATIONS AND DECISIONS BY SURROGATES AND HEALTH CARE  
36 PROVIDERS PURSUANT TO THIS ARTICLE.

37 2. IF A DECISION TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT HAS  
38 BEEN MADE PURSUANT TO THIS ARTICLE, AND AN ATTENDING PHYSICIAN DETER-  
39 MINES AT ANY TIME THAT THE DECISION IS NO LONGER APPROPRIATE OR AUTHOR-  
40 IZED BECAUSE THE PATIENT HAS REGAINED DECISION-MAKING CAPACITY OR  
41 BECAUSE THE PATIENT'S CONDITION HAS OTHERWISE IMPROVED, THE PHYSICIAN  
42 SHALL IMMEDIATELY:

43 (A) INCLUDE SUCH DETERMINATION IN THE PATIENT'S MEDICAL RECORD;

44 (B) CANCEL ANY ORDERS OR PLANS OF CARE IMPLEMENTING THE DECISION TO  
45 WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT;

46 (C) NOTIFY THE PERSON WHO MADE THE DECISION TO WITHHOLD OR WITHDRAW  
47 TREATMENT, OR, IF THAT PERSON IS NOT REASONABLY AVAILABLE, TO AT LEAST  
48 ONE PERSON ON THE SURROGATE LIST HIGHEST IN ORDER OF PRIORITY LISTED  
49 WHEN PERSONS IN PRIOR CLASSES ARE NOT REASONABLY AVAILABLE PURSUANT TO  
50 SUBDIVISION ONE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS  
51 ARTICLE; AND

52 (D) NOTIFY THE HOSPITAL STAFF DIRECTLY RESPONSIBLE FOR THE PATIENT'S  
53 CARE OF ANY CANCELLED ORDERS OR PLANS OF CARE.

54 S 2994-L. INTERINSTITUTIONAL TRANSFERS. IF A PATIENT WITH AN ORDER TO  
55 WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT IS TRANSFERRED FROM A  
56 MENTAL HYGIENE FACILITY OR FROM A HOSPITAL TO A DIFFERENT HOSPITAL, ANY

1 SUCH ORDER OR PLAN SHALL REMAIN EFFECTIVE UNTIL AN ATTENDING PHYSICIAN  
2 FIRST EXAMINES THE TRANSFERRED PATIENT, WHEREUPON AN ATTENDING PHYSICIAN  
3 MUST EITHER:

4 1. ISSUE APPROPRIATE ORDERS TO CONTINUE THE PRIOR ORDER OR PLAN. SUCH  
5 ORDERS MAY BE ISSUED WITHOUT OBTAINING ANOTHER CONSENT TO WITHHOLD OR  
6 WITHDRAW LIFE-SUSTAINING TREATMENT PURSUANT TO THIS ARTICLE; OR

7 2. CANCEL SUCH ORDER, IF THE ATTENDING PHYSICIAN DETERMINES THAT THE  
8 ORDER IS NO LONGER APPROPRIATE OR AUTHORIZED. BEFORE CANCELING THE ORDER  
9 THE ATTENDING PHYSICIAN SHALL MAKE REASONABLE EFFORTS TO NOTIFY THE  
10 PERSON WHO MADE THE DECISION TO WITHHOLD OR WITHDRAW TREATMENT AND THE  
11 HOSPITAL STAFF DIRECTLY RESPONSIBLE FOR THE PATIENT'S CARE OF ANY SUCH  
12 CANCELLATION. IF SUCH NOTICE CANNOT REASONABLY BE MADE PRIOR TO CANCEL-  
13 ING THE ORDER OR PLAN, THE ATTENDING PHYSICIAN SHALL MAKE SUCH NOTICE AS  
14 SOON AS REASONABLY PRACTICABLE AFTER CANCELLATION.

15 S 2994-M. ETHICS REVIEW COMMITTEES. 1. ESTABLISHMENT OF AN ETHICS  
16 REVIEW COMMITTEE, WRITTEN POLICY. EACH HOSPITAL SHALL ESTABLISH AT LEAST  
17 ONE ETHICS REVIEW COMMITTEE OR PARTICIPATE IN AN ETHICS REVIEW COMMITTEE  
18 THAT SERVES MORE THAN ONE HOSPITAL, AND SHALL ADOPT A WRITTEN POLICY  
19 GOVERNING COMMITTEE FUNCTIONS, COMPOSITION, AND PROCEDURE, IN ACCORDANCE  
20 WITH THE REQUIREMENTS OF THIS ARTICLE. A HOSPITAL MAY DESIGNATE AN  
21 EXISTING COMMITTEE, OR SUBCOMMITTEE THEREOF, TO CARRY OUT THE FUNCTIONS  
22 OF THE ETHICS REVIEW COMMITTEE PROVIDED THE REQUIREMENTS OF THIS SECTION  
23 ARE SATISFIED.

24 2. FUNCTIONS OF THE ETHICS REVIEW COMMITTEE. (A) THE ETHICS REVIEW  
25 COMMITTEE SHALL CONSIDER AND RESPOND TO ANY HEALTH CARE MATTER PRESENTED  
26 TO IT BY A PERSON CONNECTED WITH THE CASE.

27 (B) THE ETHICS REVIEW COMMITTEE RESPONSE TO A HEALTH CARE MATTER MAY  
28 INCLUDE:

29 (I) PROVIDING ADVICE ON THE ETHICAL ASPECTS OF PROPOSED HEALTH CARE;

30 (II) MAKING A RECOMMENDATION ABOUT PROPOSED HEALTH CARE; OR

31 (III) PROVIDING ASSISTANCE IN RESOLVING DISPUTES ABOUT PROPOSED HEALTH  
32 CARE.

33 (C) RECOMMENDATIONS AND ADVICE BY THE ETHICS REVIEW COMMITTEE SHALL BE  
34 ADVISORY AND NONBINDING, EXCEPT AS SPECIFIED IN SUBDIVISION FIVE OF  
35 SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE AND SUBDIVI-  
36 SION THREE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-E OF THIS ARTICLE.

37 3. COMMITTEE MEMBERSHIP. IN A RESIDENTIAL HEALTH CARE FACILITY THE  
38 ETHICS REVIEW COMMITTEE SHALL HAVE AT LEAST FIVE MEMBERS. AT LEAST THREE  
39 COMMITTEE MEMBERS MUST BE HEALTH OR SOCIAL SERVICES PRACTITIONERS, AT  
40 LEAST ONE OF WHOM MUST BE A REGISTERED NURSE AND ONE OF WHOM MUST BE A  
41 PHYSICIAN. AT LEAST TWO COMMITTEE MEMBERS MUST BE MEMBERS OF THE RESI-  
42 DENTS' COUNCIL OF THE FACILITY (OR OF ANOTHER FACILITY THAT PARTICIPATES  
43 IN THE COMMITTEE) OR BE A PERSON NOT AFFILIATED WITH THE FACILITY WHO IS  
44 A FAMILY MEMBER OF A CURRENT OR FORMER RESIDENT AT THE SAME OR ANOTHER  
45 RESIDENTIAL HEALTH CARE FACILITY OR A PERSON WHO HAS EXPERTISE IN OR A  
46 DEMONSTRATED COMMITMENT TO PATIENT RIGHTS OR TO THE CARE AND TREATMENT  
47 OF THE ELDERLY OR NURSING HOME RESIDENTS THROUGH PROFESSIONAL OR COMMU-  
48 NITY ACTIVITIES, OTHER THAN ACTIVITIES PERFORMED AS A HEALTH CARE  
49 PROVIDER.

50 4. PROCEDURES FOR ETHICS REVIEW COMMITTEE. (A) THESE PROCEDURES ARE  
51 REQUIRED ONLY WHEN (I) THE ETHICS REVIEW COMMITTEE IS CONVENED TO REVIEW  
52 A DECISION BY A SURROGATE TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREAT-  
53 MENT FOR (A) A PATIENT IN A RESIDENTIAL HEALTH CARE FACILITY PURSUANT TO  
54 PARAGRAPH (B) OF SUBDIVISION FIVE OF SECTION TWENTY-NINE HUNDRED NINE-  
55 TY-FOUR-D OF THIS ARTICLE, (B) A PATIENT IN A GENERAL HOSPITAL PURSUANT  
56 TO PARAGRAPH (C) OF SUBDIVISION FIVE OF SECTION TWENTY-NINE HUNDRED

1 NINETY-FOUR-D OF THIS ARTICLE, OR (C) AN EMANCIPATED MINOR PATIENT  
2 PURSUANT TO SUBDIVISION THREE OF SECTION TWENTY-NINE HUNDRED  
3 NINETY-FOUR-E OF THIS ARTICLE; OR (II) WHEN A PERSON CONNECTED WITH THE  
4 CASE REQUESTS THE ETHICS REVIEW COMMITTEE TO PROVIDE ASSISTANCE IN  
5 RESOLVING A DISPUTE ABOUT PROPOSED CARE. NOTHING IN THIS SECTION SHALL  
6 BAR HEALTH CARE PROVIDERS FROM FIRST STRIVING TO RESOLVE DISPUTES  
7 THROUGH LESS FORMAL MEANS, INCLUDING THE INFORMAL SOLICITATION OF  
8 ETHICAL ADVICE FROM ANY SOURCE.

9 (B)(I) A PERSON CONNECTED WITH THE CASE MAY NOT PARTICIPATE AS AN  
10 ETHICS REVIEW COMMITTEE MEMBER IN THE CONSIDERATION OF THAT CASE.

11 (II) THE ETHICS REVIEW COMMITTEE SHALL RESPOND PROMPTLY, AS REQUIRED  
12 BY THE CIRCUMSTANCES, TO ANY REQUEST FOR ASSISTANCE IN RESOLVING A  
13 DISPUTE OR CONSIDERATION OF A DECISION TO WITHHOLD OR WITHDRAW LIFE-SUS-  
14 TAINING TREATMENT PURSUANT TO PARAGRAPHS (B) AND (C) OF SUBDIVISION FIVE  
15 OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE MADE BY A  
16 PERSON CONNECTED WITH THE CASE. THE COMMITTEE SHALL PERMIT PERSONS  
17 CONNECTED WITH THE CASE TO PRESENT THEIR VIEWS TO THE COMMITTEE, AND TO  
18 HAVE THE OPTION OF BEING ACCOMPANIED BY AN ADVISOR WHEN PARTICIPATING IN  
19 A COMMITTEE MEETING.

20 (III) THE ETHICS REVIEW COMMITTEE SHALL PROMPTLY PROVIDE THE PATIENT,  
21 WHERE THERE IS ANY INDICATION OF THE PATIENT'S ABILITY TO COMPREHEND THE  
22 INFORMATION, THE SURROGATE, OTHER PERSONS ON THE SURROGATE LIST DIRECTLY  
23 INVOLVED IN THE DECISION OR DISPUTE REGARDING THE PATIENT'S CARE, ANY  
24 PARENT OR GUARDIAN OF A MINOR PATIENT DIRECTLY INVOLVED IN THE DECISION  
25 OR DISPUTE REGARDING THE MINOR PATIENT'S CARE, AN ATTENDING PHYSICIAN,  
26 THE HOSPITAL, AND OTHER PERSONS THE COMMITTEE DEEMS APPROPRIATE, WITH  
27 THE FOLLOWING:

28 (A) NOTICE OF ANY PENDING CASE CONSIDERATION CONCERNING THE PATIENT,  
29 INCLUDING, FOR PATIENTS, PERSONS ON THE SURROGATE LIST, PARENTS AND  
30 GUARDIANS, INFORMATION ABOUT THE ETHICS REVIEW COMMITTEE'S PROCEDURES,  
31 COMPOSITION AND FUNCTION; AND

32 (B) THE COMMITTEE'S RESPONSE TO THE CASE, INCLUDING A WRITTEN STATE-  
33 MENT OF THE REASONS FOR APPROVING OR DISAPPROVING THE WITHHOLDING OR  
34 WITHDRAWAL OF LIFE-SUSTAINING TREATMENT FOR DECISIONS CONSIDERED PURSU-  
35 ANT TO SUBPARAGRAPH (II) OF PARAGRAPH (A) OF SUBDIVISION FIVE OF SECTION  
36 TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE. THE COMMITTEE'S  
37 RESPONSE TO THE CASE SHALL BE INCLUDED IN THE PATIENT'S MEDICAL RECORD.

38 (IV) FOLLOWING ETHICS REVIEW COMMITTEE CONSIDERATION OF A CASE  
39 CONCERNING THE WITHDRAWAL OR WITHHOLDING OF LIFE-SUSTAINING TREATMENT,  
40 TREATMENT SHALL NOT BE WITHDRAWN OR WITHHELD UNTIL THE PERSONS IDENTI-  
41 FIED IN SUBPARAGRAPH (III) OF THIS PARAGRAPH HAVE BEEN INFORMED OF THE  
42 COMMITTEE'S RESPONSE TO THE CASE.

43 5. ACCESS TO MEDICAL RECORDS AND INFORMATION; PATIENT CONFIDENTIALITY.  
44 ETHICS REVIEW COMMITTEE MEMBERS AND CONSULTANTS SHALL HAVE ACCESS TO  
45 MEDICAL INFORMATION AND MEDICAL RECORDS NECESSARY TO PERFORM THEIR FUNC-  
46 TION UNDER THIS ARTICLE. ANY SUCH INFORMATION OR RECORDS DISCLOSED TO  
47 COMMITTEE MEMBERS, CONSULTANTS, OR OTHERS SHALL BE KEPT CONFIDENTIAL  
48 EXCEPT TO THE EXTENT NECESSARY TO ACCOMPLISH THE PURPOSES OF THIS ARTI-  
49 CLE OR AS OTHERWISE PROVIDED BY LAW.

50 6. ETHICS REVIEW COMMITTEE CONFIDENTIALITY. NOTWITHSTANDING ANY OTHER  
51 PROVISIONS OF LAW, THE PROCEEDINGS AND RECORDS OF AN ETHICS REVIEW  
52 COMMITTEE SHALL BE KEPT CONFIDENTIAL AND SHALL NOT BE RELEASED BY  
53 COMMITTEE MEMBERS, COMMITTEE CONSULTANTS, OR OTHER PERSONS PRIVY TO SUCH  
54 PROCEEDINGS AND RECORDS; THE PROCEEDINGS AND RECORDS OF AN ETHICS REVIEW  
55 COMMITTEE SHALL NOT BE SUBJECT TO DISCLOSURE OR INSPECTION IN ANY  
56 MANNER, INCLUDING UNDER ARTICLE SIX OF THE PUBLIC OFFICERS LAW OR ARTI-

1 CLE THIRTY-ONE OF THE CIVIL PRACTICE LAW AND RULES; AND, NO PERSON SHALL  
2 TESTIFY AS TO THE PROCEEDINGS OR RECORDS OF AN ETHICS REVIEW COMMITTEE,  
3 NOR SHALL SUCH PROCEEDINGS AND RECORDS OTHERWISE BE ADMISSIBLE AS  
4 EVIDENCE IN ANY ACTION OR PROCEEDING OF ANY KIND IN ANY COURT OR BEFORE  
5 ANY OTHER TRIBUNAL, BOARD, AGENCY OR PERSON, EXCEPT THAT:

6 (A) ETHICS REVIEW COMMITTEE PROCEEDINGS AND RECORDS, IN CASES WHERE A  
7 COMMITTEE APPROVES OR DISAPPROVES OF THE WITHHOLDING OR WITHDRAWAL OF  
8 LIFE-SUSTAINING TREATMENT PURSUANT TO SUBDIVISION FIVE OF SECTION TWEN-  
9 TY-NINE HUNDRED NINETY-FOUR-D OF THIS ARTICLE, OR SUBDIVISION THREE OF  
10 SECTION TWENTY-NINE HUNDRED NINETY-FOUR-E OF THIS ARTICLE, MAY BE  
11 OBTAINED BY OR RELEASED TO THE DEPARTMENT;

12 (B) NOTHING IN THIS SUBDIVISION SHALL PROHIBIT THE PATIENT, THE SURRO-  
13 GATE, OTHER PERSONS ON THE SURROGATE LIST, OR A PARENT OR GUARDIAN OF A  
14 MINOR PATIENT FROM VOLUNTARILY DISCLOSING, RELEASING OR TESTIFYING ABOUT  
15 COMMITTEE PROCEEDINGS OR RECORDS; AND

16 (C) NOTHING IN THIS SUBDIVISION SHALL PROHIBIT THE STATE COMMISSION ON  
17 QUALITY OF CARE FOR THE MENTALLY DISABLED FROM REQUIRING ANY INFORMA-  
18 TION, REPORT OR RECORD FROM A HOSPITAL IN ACCORDANCE WITH THE PROVISIONS  
19 OF SECTION 45.09 OF THE MENTAL HYGIENE LAW.

20 S 2994-N. CONSCIENCE OBJECTIONS. 1. PRIVATE HOSPITALS. NOTHING IN THIS  
21 ARTICLE SHALL BE CONSTRUED TO REQUIRE A PRIVATE HOSPITAL TO HONOR A  
22 HEALTH CARE DECISION MADE PURSUANT TO THIS ARTICLE IF:

23 (A) THE DECISION IS CONTRARY TO A FORMALLY ADOPTED POLICY OF THE  
24 HOSPITAL THAT IS EXPRESSLY BASED ON SINCERELY HELD RELIGIOUS BELIEFS OR  
25 SINCERELY HELD MORAL CONVICTIONS CENTRAL TO THE FACILITY'S OPERATING  
26 PRINCIPLES;

27 (B) THE HOSPITAL HAS INFORMED THE PATIENT, FAMILY, OR SURROGATE OF  
28 SUCH POLICY PRIOR TO OR UPON ADMISSION, IF REASONABLY POSSIBLE; AND

29 (C) THE PATIENT IS TRANSFERRED PROMPTLY TO ANOTHER HOSPITAL THAT IS  
30 REASONABLY ACCESSIBLE UNDER THE CIRCUMSTANCES AND WILLING TO HONOR THE  
31 DECISION AND PENDING TRANSFER THE HOSPITAL COMPLIES WITH SUBDIVISION  
32 THREE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-F OF THIS ARTICLE. IF  
33 THE PATIENT'S FAMILY OR SURROGATE IS UNABLE OR UNWILLING TO ARRANGE SUCH  
34 A TRANSFER, THE HOSPITAL MAY INTERVENE TO FACILITATE SUCH A TRANSFER. IF  
35 SUCH A TRANSFER IS NOT EFFECTED, THE HOSPITAL SHALL SEEK JUDICIAL RELIEF  
36 IN ACCORDANCE WITH SECTION TWENTY-NINE HUNDRED NINETY-FOUR-R OF THIS  
37 ARTICLE OR HONOR THE DECISION.

38 2. INDIVIDUAL HEALTH CARE PROVIDERS. NOTHING IN THIS ARTICLE SHALL BE  
39 CONSTRUED TO REQUIRE AN INDIVIDUAL AS A HEALTH CARE PROVIDER TO HONOR A  
40 HEALTH CARE DECISION MADE PURSUANT TO THIS ARTICLE IF:

41 (A) THE DECISION IS CONTRARY TO THE INDIVIDUAL'S SINCERELY HELD RELI-  
42 GIOUS BELIEFS OR SINCERELY HELD MORAL CONVICTION; AND

43 (B) THE INDIVIDUAL HEALTH CARE PROVIDER PROMPTLY INFORMS THE PERSON  
44 WHO MADE THE DECISION AND THE HOSPITAL OF HIS OR HER REFUSAL TO HONOR  
45 THE DECISION. IN SUCH EVENT, THE HOSPITAL SHALL PROMPTLY TRANSFER  
46 RESPONSIBILITY FOR THE PATIENT TO ANOTHER INDIVIDUAL HEALTH CARE PROVID-  
47 ER WILLING TO HONOR THE DECISION. THE INDIVIDUAL HEALTH CARE PROVIDER  
48 SHALL COOPERATE IN FACILITATING SUCH TRANSFER AND COMPLY WITH SUBDIVI-  
49 SION THREE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-F OF THIS ARTICLE.

50 S 2994-O. IMMUNITY. 1. ETHICS REVIEW COMMITTEE. NO PERSON SHALL BE  
51 SUBJECT TO CRIMINAL OR CIVIL LIABILITY, OR BE DEEMED TO HAVE ENGAGED IN  
52 UNPROFESSIONAL CONDUCT, FOR ACTS PERFORMED REASONABLY AND IN GOOD FAITH  
53 PURSUANT TO THIS ARTICLE AS A MEMBER OF OR AS A CONSULTANT TO AN ETHICS  
54 REVIEW COMMITTEE OR AS A PARTICIPANT IN AN ETHICS REVIEW COMMITTEE MEET-  
55 ING.

1 2. PROVIDERS. NO HEALTH CARE PROVIDER OR EMPLOYEE THEREOF SHALL BE  
2 SUBJECTED TO CRIMINAL OR CIVIL LIABILITY, OR BE DEEMED TO HAVE ENGAGED  
3 IN UNPROFESSIONAL CONDUCT, FOR HONORING REASONABLY AND IN GOOD FAITH A  
4 HEALTH CARE DECISION MADE PURSUANT TO THIS ARTICLE OR FOR OTHER ACTIONS  
5 TAKEN REASONABLY AND IN GOOD FAITH PURSUANT TO THIS ARTICLE.

6 3. SURROGATES AND GUARDIANS. NO PERSON SHALL BE SUBJECTED TO CRIMINAL  
7 OR CIVIL LIABILITY FOR MAKING A HEALTH CARE DECISION REASONABLY AND IN  
8 GOOD FAITH PURSUANT TO THIS ARTICLE OR FOR OTHER ACTIONS TAKEN REASON-  
9 ABLY AND IN GOOD FAITH PURSUANT TO THIS ARTICLE.

10 S 2994-P. LIABILITY FOR HEALTH CARE COSTS. LIABILITY FOR THE COST OF  
11 HEALTH CARE PROVIDED TO AN ADULT PATIENT PURSUANT TO THIS ARTICLE SHALL  
12 BE THE SAME AS IF THE HEALTH CARE WERE PROVIDED PURSUANT TO THE  
13 PATIENT'S DECISION. NO PERSON SHALL BECOME LIABLE FOR THE COST OF HEALTH  
14 CARE FOR A MINOR SOLELY BY VIRTUE OF MAKING A DECISION AS A GUARDIAN OF  
15 A MINOR PURSUANT TO THIS ARTICLE.

16 S 2994-Q. EFFECT ON OTHER RIGHTS. 1. NOTHING IN THIS ARTICLE CREATES,  
17 EXPANDS, DIMINISHES, IMPAIRS, OR SUPERSEDES ANY AUTHORITY THAT AN INDI-  
18 VIDUAL MAY HAVE UNDER LAW TO MAKE OR EXPRESS DECISIONS, WISHES, OR  
19 INSTRUCTIONS REGARDING HEALTH CARE ON HIS OR HER OWN BEHALF, INCLUDING  
20 DECISIONS ABOUT LIFE-SUSTAINING TREATMENT.

21 2. NOTHING IN THIS ARTICLE SHALL AFFECT EXISTING LAW CONCERNING  
22 IMPLIED CONSENT TO HEALTH CARE IN AN EMERGENCY.

23 3. NOTHING IN THIS ARTICLE IS INTENDED TO PERMIT OR PROMOTE SUICIDE,  
24 ASSISTED SUICIDE, OR EUTHANASIA.

25 4. THIS ARTICLE SHALL NOT AFFECT EXISTING LAW WITH RESPECT TO STERILI-  
26 ZATION.

27 5. NOTHING IN THIS ARTICLE DIMINISHES THE DUTY OF PARENTS AND LEGAL  
28 GUARDIANS UNDER EXISTING LAW TO CONSENT TO TREATMENT FOR MINORS.

29 S 2994-R. SPECIAL PROCEEDING AUTHORIZED; COURT ORDERS; HEALTH CARE  
30 GUARDIAN FOR MINOR PATIENT. 1. SPECIAL PROCEEDING. ANY PERSON CONNECTED  
31 WITH THE CASE AND ANY MEMBER OF THE HOSPITAL ETHICS REVIEW COMMITTEE MAY  
32 COMMENCE A SPECIAL PROCEEDING IN A COURT OF COMPETENT JURISDICTION WITH  
33 RESPECT TO ANY MATTER ARISING UNDER THIS ARTICLE.

34 2. COURT ORDERS DESIGNATING SURROGATE. A COURT OF COMPETENT JURISDIC-  
35 TION MAY DESIGNATE ANY INDIVIDUAL FROM THE SURROGATE LIST TO ACT AS  
36 SURROGATE, REGARDLESS OF THAT INDIVIDUAL'S PRIORITY ON THE LIST, IF THE  
37 COURT DETERMINES THAT SUCH APPOINTMENT WOULD BEST ACCORD WITH THE  
38 PATIENT'S WISHES OR, IF THE PATIENT'S WISHES ARE NOT REASONABLY KNOWN,  
39 WITH THE PATIENT'S BEST INTERESTS. UNLESS OTHERWISE DETERMINED BY A  
40 COURT, NO SURROGATE DECISION MADE PRIOR TO AN ORDER DESIGNATING A SURRO-  
41 GATE SHALL BE DEEMED TO HAVE BEEN INVALID BECAUSE OF THE ISSUANCE OF A  
42 DESIGNATING ORDER.

43 3. COURT ORDERS TO WITHHOLD OR WITHDRAW LIFE-SUSTAINING TREATMENT. A  
44 COURT OF COMPETENT JURISDICTION MAY AUTHORIZE THE WITHHOLDING OR WITH-  
45 DRAWAL OF LIFE-SUSTAINING TREATMENT FROM A PERSON IF THE COURT DETER-  
46 MINES THAT THE PERSON LACKS DECISION-MAKING CAPACITY, AND WITHDRAWING OR  
47 WITHHOLDING THE TREATMENT WOULD ACCORD WITH THE STANDARDS SET FORTH IN  
48 SUBDIVISION FIVE OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-D OF THIS  
49 ARTICLE.

50 4. HEALTH CARE GUARDIAN FOR A MINOR PATIENT. (A) NO APPOINTMENT SHALL  
51 BE MADE PURSUANT TO THIS SUBDIVISION IF A PARENT OR LEGAL GUARDIAN OF  
52 THE PERSON IS AVAILABLE, WILLING, AND COMPETENT TO DECIDE ABOUT TREAT-  
53 MENT FOR THE MINOR.

54 (B) THE FOLLOWING PERSONS MAY COMMENCE A SPECIAL PROCEEDING IN A COURT  
55 OF COMPETENT JURISDICTION TO SEEK APPOINTMENT AS THE HEALTH CARE GUARDI-

1 AN OF A MINOR PATIENT SOLELY FOR THE PURPOSE OF DECIDING ABOUT LIFE-SUS-  
2 TAINING TREATMENT PURSUANT TO THIS ARTICLE:

3 (I) THE HOSPITAL ADMINISTRATOR;

4 (II) AN ATTENDING PHYSICIAN;

5 (III) THE LOCAL COMMISSIONER OF SOCIAL SERVICES OR THE LOCAL COMMIS-  
6 SIONER OF HEALTH, AUTHORIZED TO MAKE MEDICAL TREATMENT DECISIONS FOR THE  
7 MINOR PURSUANT TO SECTION THREE HUNDRED EIGHTY-THREE-B OF THE SOCIAL  
8 SERVICES LAW; OR

9 (IV) AN INDIVIDUAL, EIGHTEEN YEARS OF AGE OR OLDER, WHO HAS ASSUMED  
10 CARE OF THE MINOR FOR A SUBSTANTIAL AND CONTINUOUS PERIOD OF TIME.

11 (C) NOTICE OF THE PROCEEDING SHALL BE GIVEN TO THE PERSONS IDENTIFIED  
12 IN SECTION ONE THOUSAND SEVEN HUNDRED FIVE OF THE SURROGATE'S COURT  
13 PROCEDURE ACT.

14 (D) NOTWITHSTANDING ANY OTHER PROVISION OF LAW, SEEKING APPOINTMENT OR  
15 BEING APPOINTED AS A HEALTH CARE GUARDIAN SHALL NOT OTHERWISE AFFECT THE  
16 LEGAL STATUS OR RIGHTS OF THE INDIVIDUAL SEEKING OR OBTAINING SUCH  
17 APPOINTMENT.

18 S 2994-S. REMEDY. 1. ANY HOSPITAL OR ATTENDING PHYSICIAN THAT REFUSES  
19 TO HONOR A HEALTH CARE DECISION BY A SURROGATE MADE PURSUANT TO THIS  
20 ARTICLE AND IN ACCORD WITH THE STANDARDS SET FORTH IN THIS ARTICLE SHALL  
21 NOT BE ENTITLED TO COMPENSATION FOR TREATMENT, SERVICES, OR PROCEDURES  
22 REFUSED BY THE SURROGATE, EXCEPT THAT THIS SUBDIVISION SHALL NOT APPLY:

23 (A) WHEN A HOSPITAL OR PHYSICIAN EXERCISES THE RIGHTS GRANTED BY  
24 SECTION TWENTY-NINE HUNDRED NINETY-FOUR-N OF THIS ARTICLE, PROVIDED THAT  
25 THE PHYSICIAN OR HOSPITAL PROMPTLY FULFILLS THE OBLIGATIONS SET FORTH IN  
26 SECTION TWENTY-NINE HUNDRED NINETY-FOUR-N OF THIS ARTICLE;

27 (B) WHILE A MATTER IS UNDER CONSIDERATION BY THE ETHICS REVIEW COMMIT-  
28 TEE, PROVIDED THAT THE MATTER IS PROMPTLY REFERRED TO AND CONSIDERED BY  
29 THE COMMITTEE;

30 (C) IN THE EVENT OF A DISPUTE BETWEEN INDIVIDUALS ON THE SURROGATE  
31 LIST; OR

32 (D) IF THE PHYSICIAN OR HOSPITAL PREVAILS IN ANY LITIGATION CONCERNING  
33 THE SURROGATE'S DECISION TO REFUSE THE TREATMENT, SERVICES OR PROCEDURE.  
34 NOTHING IN THIS SECTION SHALL DETERMINE OR AFFECT HOW DISPUTES AMONG  
35 INDIVIDUALS ON THE SURROGATE LIST ARE RESOLVED.

36 2. THE REMEDY PROVIDED IN THIS SECTION IS IN ADDITION TO AND CUMULA-  
37 TIVE WITH ANY OTHER REMEDIES AVAILABLE AT LAW OR IN EQUITY OR BY ADMIN-  
38 ISTRATIVE PROCEEDINGS TO A PATIENT, A HEALTH CARE AGENT APPOINTED PURSU-  
39 ANT TO ARTICLE TWENTY-NINE-C OF THIS CHAPTER, OR A PERSON AUTHORIZED TO  
40 MAKE HEALTH CARE DECISIONS PURSUANT TO THIS ARTICLE, INCLUDING INJUNC-  
41 TIVE AND DECLARATORY RELIEF, AND ANY OTHER PROVISIONS OF THIS CHAPTER  
42 GOVERNING FINES, PENALTIES, OR FORFEITURES.

43 S 2994-T. REGULATIONS. 1. THE COMMISSIONER SHALL ESTABLISH SUCH REGU-  
44 LATIONS AS MAY BE NECESSARY TO IMPLEMENT THIS ARTICLE.

45 2. THE COMMISSIONER, IN CONSULTATION WITH THE COMMISSIONERS OF THE  
46 OFFICE OF MENTAL HEALTH AND THE OFFICE OF MENTAL RETARDATION AND DEVEL-  
47 OPMENTAL DISABILITIES, SHALL PROMULGATE REGULATIONS IDENTIFYING THE  
48 CREDENTIALS OF HEALTH CARE PROFESSIONALS QUALIFIED TO PROVIDE AN INDE-  
49 PENDENT DETERMINATION, PURSUANT TO SUBDIVISION THREE OF SECTION TWENTY-  
50 NINE HUNDRED NINETY-FOUR-C OF THIS ARTICLE, THAT A PATIENT LACKS DECI-  
51 SION-MAKING CAPACITY BECAUSE OF MENTAL ILLNESS OR DEVELOPMENTAL  
52 DISABILITY.

53 S 2994-U. RIGHTS TO BE PUBLICIZED. THE COMMISSIONER SHALL PREPARE A  
54 STATEMENT SUMMARIZING THE RIGHTS, DUTIES, AND REQUIREMENTS OF THIS ARTI-  
55 CLE AND SHALL REQUIRE THAT A COPY OF SUCH STATEMENT BE FURNISHED TO  
56 PATIENTS OR TO PERSONS ON THE SURROGATE LIST KNOWN TO THE HOSPITAL, OR

1 TO THE PARENTS OR GUARDIANS OF MINOR PATIENTS, AT OR PRIOR TO ADMISSION  
2 TO THE HOSPITAL, OR WITHIN A REASONABLE TIME THEREAFTER, AND TO EACH  
3 MEMBER OF THE HOSPITAL'S STAFF DIRECTLY INVOLVED WITH PATIENT CARE.

4 ARTICLE 29-CCC

5 NONHOSPITAL ORDERS NOT TO RESUSCITATE

6 SECTION 2994-AA. DEFINITIONS.

7 2994-BB. GENERAL PROVISIONS.

8 2994-CC. CONSENT TO A NONHOSPITAL ORDER NOT TO RESUSCITATE.

9 2994-DD. MANAGING A NONHOSPITAL ORDER NOT TO RESUSCITATE.

10 2994-EE. OBLIGATION TO HONOR A NONHOSPITAL ORDER NOT TO RESUSCI-  
11 TATE.

12 2994-FF. INTERINSTITUTIONAL TRANSFER.

13 2994-GG. IMMUNITY.

14 S 2994-AA. DEFINITIONS. 1. "ADULT" MEANS ANY PERSON WHO IS EIGHTEEN  
15 YEARS OF AGE OR OLDER, OR IS THE PARENT OF A CHILD OR HAS MARRIED.

16 2. "ATTENDING PHYSICIAN" MEANS THE PHYSICIAN WHO HAS PRIMARY RESPONSI-  
17 BILITY FOR THE TREATMENT AND CARE OF THE PATIENT. WHERE MORE THAN ONE  
18 PHYSICIAN SHARES SUCH RESPONSIBILITY, ANY SUCH PHYSICIAN MAY ACT AS THE  
19 ATTENDING PHYSICIAN PURSUANT TO THIS ARTICLE.

20 3. "CAPACITY" MEANS THE ABILITY TO UNDERSTAND AND APPRECIATE THE  
21 NATURE AND CONSEQUENCES OF A NONHOSPITAL ORDER NOT TO RESUSCITATE,  
22 INCLUDING THE BENEFITS AND DISADVANTAGES OF SUCH AN ORDER, AND TO REACH  
23 AN INFORMED DECISION REGARDING THE ORDER.

24 4. "CARDIOPULMONARY RESUSCITATION" MEANS MEASURES, AS SPECIFIED IN  
25 REGULATIONS PROMULGATED BY THE COMMISSIONER, TO RESTORE CARDIAC FUNCTION  
26 OR TO SUPPORT VENTILATION IN THE EVENT OF A CARDIAC OR RESPIRATORY  
27 ARREST. SUCH TERM SHALL NOT INCLUDE MEASURES TO IMPROVE VENTILATION AND  
28 CARDIAC FUNCTION IN THE ABSENCE OF AN ARREST.

29 5. "EMERGENCY MEDICAL SERVICES PERSONNEL" MEANS THE PERSONNEL OF A  
30 SERVICE OR AGENCY ENGAGED IN PROVIDING INITIAL EMERGENCY MEDICAL ASSIST-  
31 ANCE, INCLUDING BUT NOT LIMITED TO FIRST RESPONDERS, EMERGENCY MEDICAL  
32 TECHNICIANS, ADVANCED EMERGENCY MEDICAL TECHNICIANS AND PERSONNEL  
33 ENGAGED IN PROVIDING HEALTH CARE AT CORRECTIONAL FACILITIES, AS THAT  
34 TERM IS DEFINED IN SUBDIVISION FOUR OF SECTION TWO OF THE CORRECTION  
35 LAW.

36 6. "HEALTH CARE AGENT" MEANS A HEALTH CARE AGENT OF THE PATIENT DESIG-  
37 NATED PURSUANT TO ARTICLE TWENTY-NINE-C OF THIS CHAPTER.

38 7. "HEALTH OR SOCIAL SERVICES PRACTITIONER" MEANS A REGISTERED PROFES-  
39 SIONAL NURSE, NURSE PRACTITIONER, PHYSICIAN, PHYSICIAN ASSISTANT,  
40 PSYCHOLOGIST OR CERTIFIED SOCIAL WORKER LICENSED OR CERTIFIED PURSUANT  
41 TO THE EDUCATION LAW AND QUALIFIED TO PROVIDE A SECOND OPINION OF CAPAC-  
42 ITY AS SPECIFIED IN REGULATIONS PROMULGATED BY THE COMMISSIONER.

43 8. "HOSPITAL" MEANS A GENERAL HOSPITAL AS DEFINED IN SUBDIVISION TEN  
44 OF SECTION TWENTY-EIGHT HUNDRED ONE OF THIS CHAPTER AND A RESIDENTIAL  
45 HEALTH CARE FACILITY AS DEFINED IN SUBDIVISION THREE OF SECTION TWENTY-  
46 EIGHT HUNDRED ONE OF THIS CHAPTER OR A HOSPITAL AS DEFINED IN SUBDIVI-  
47 SION TEN OF SECTION 1.03 OF THE MENTAL HYGIENE LAW OR A SCHOOL NAMED IN  
48 SECTION 13.17 OF THE MENTAL HYGIENE LAW.

49 9. "HOSPITAL EMERGENCY SERVICES PERSONNEL" MEANS THE PERSONNEL OF THE  
50 EMERGENCY SERVICE OF A GENERAL HOSPITAL, AS DEFINED IN SUBDIVISION TEN  
51 OF SECTION TWENTY-EIGHT HUNDRED ONE OF THIS CHAPTER, INCLUDING BUT NOT  
52 LIMITED TO EMERGENCY SERVICES ATTENDING PHYSICIANS, EMERGENCY SERVICES  
53 REGISTERED PROFESSIONAL NURSES, AND REGISTERED PROFESSIONAL NURSES,  
54 NURSING STAFF AND REGISTERED PHYSICIANS ASSISTANTS ASSIGNED TO THE  
55 GENERAL HOSPITAL'S EMERGENCY SERVICE.

1 10. "MENTAL HYGIENE FACILITY" MEANS A RESIDENTIAL FACILITY OPERATED OR  
2 LICENSED BY THE OFFICE OF MENTAL HEALTH OR THE OFFICE OF MENTAL RETARDA-  
3 TION AND DEVELOPMENTAL DISABILITIES.

4 11. "NONHOSPITAL ORDER NOT TO RESUSCITATE" MEANS AN ORDER THAT DIRECTS  
5 EMERGENCY MEDICAL SERVICES PERSONNEL AND HOSPITAL EMERGENCY SERVICES  
6 PERSONNEL NOT TO ATTEMPT CARDIOPULMONARY RESUSCITATION IN THE EVENT A  
7 PATIENT SUFFERS CARDIAC OR RESPIRATORY ARREST.

8 12. "PATIENT" MEANS A PERSON WHO HAS BEEN OR WHO MAY BE ISSUED A  
9 NONHOSPITAL ORDER NOT TO RESUSCITATE.

10 13. "SURROGATE" MEANS A PERSON OR COMMITTEE OF PERSONS WITH THE  
11 AUTHORITY TO CONSENT TO AN ORDER NOT TO RESUSCITATE PURSUANT TO ARTICLE  
12 TWENTY-NINE-B OR TWENTY-NINE-CC OF THIS CHAPTER.

13 S 2994-BB. GENERAL PROVISIONS. 1. (A) EMERGENCY MEDICAL SERVICES  
14 PERSONNEL AND HOSPITAL EMERGENCY SERVICES PERSONNEL SHALL HONOR NONHOS-  
15 PITAL ORDERS NOT TO RESUSCITATE, EXCEPT AS PROVIDED IN SECTION  
16 TWENTY-NINE HUNDRED NINETY-FOUR-EE OF THIS ARTICLE.

17 (B) A NONHOSPITAL ORDER NOT TO RESUSCITATE SHALL NOT CONSTITUTE AN  
18 ORDER TO WITHHOLD OR WITHDRAW TREATMENT OTHER THAN CARDIOPULMONARY  
19 RESUSCITATION.

20 2. A NONHOSPITAL ORDER NOT TO RESUSCITATE MAY BE ISSUED DURING HOSPI-  
21 TALIZATION TO TAKE EFFECT AFTER HOSPITALIZATION, OR MAY BE ISSUED FOR A  
22 PERSON WHO IS NOT A PATIENT IN, OR A RESIDENT OF, A HOSPITAL.

23 S 2994-CC. CONSENT TO A NONHOSPITAL ORDER NOT TO RESUSCITATE. 1. AN  
24 ADULT WITH DECISION-MAKING CAPACITY, A HEALTH CARE AGENT, OR A SURROGATE  
25 MAY CONSENT TO A NONHOSPITAL ORDER NOT TO RESUSCITATE ORALLY TO THE  
26 ATTENDING PHYSICIAN OR IN WRITING. IF A PATIENT CONSENTS TO A NONHOSPI-  
27 TAL ORDER NOT TO RESUSCITATE WHILE IN A CORRECTIONAL FACILITY, NOTICE OF  
28 THE PATIENT'S CONSENT SHALL BE GIVEN TO THE FACILITY DIRECTOR AND  
29 REASONABLE EFFORTS SHALL BE MADE TO NOTIFY AN INDIVIDUAL DESIGNATED BY  
30 THE PATIENT TO RECEIVE SUCH NOTICE PRIOR TO THE ISSUANCE OF THE NONHOS-  
31 PITAL ORDER NOT TO RESUSCITATE. NOTIFICATION TO THE FACILITY DIRECTOR OR  
32 THE INDIVIDUAL DESIGNATED BY THE PATIENT SHALL NOT DELAY ISSUANCE OF A  
33 NONHOSPITAL ORDER NOT TO RESUSCITATE.

34 2. CONSENT BY A HEALTH CARE AGENT SHALL BE GOVERNED BY ARTICLE TWEN-  
35 TY-NINE-C OF THIS CHAPTER.

36 3. CONSENT BY A SURROGATE SHALL BE GOVERNED BY ARTICLE TWENTY-NINE-D  
37 OF THIS CHAPTER, EXCEPT THAT: (A) A SECOND DETERMINATION OF CAPACITY  
38 SHALL BE MADE BY A HEALTH OR SOCIAL SERVICES PRACTITIONER AS DEFINED IN  
39 SUBDIVISION SEVEN OF SECTION TWENTY-NINE HUNDRED NINETY-FOUR-AA OF THIS  
40 ARTICLE; AND (B) THE AUTHORITY OF THE ETHICS REVIEW COMMITTEE SET FORTH  
41 IN ARTICLE TWENTY-NINE-CC OF THIS CHAPTER SHALL APPLY ONLY TO NONHOSPI-  
42 TAL ORDERS ISSUED IN A HOSPITAL.

43 4. (A) WHEN THE CONCURRENCE OF A SECOND PHYSICIAN IS SOUGHT TO FULFILL  
44 THE REQUIREMENTS FOR THE ISSUANCE OF A NONHOSPITAL ORDER NOT TO RESUSCI-  
45 TATE FOR PATIENTS IN A CORRECTIONAL FACILITY, SUCH SECOND PHYSICIAN  
46 SHALL BE SELECTED BY THE CHIEF MEDICAL OFFICER OF THE DEPARTMENT OF  
47 CORRECTIONS OR HIS OR HER DESIGNEE.

48 (B) WHEN THE CONCURRENCE OF A SECOND PHYSICIAN IS SOUGHT TO FULFILL  
49 THE REQUIREMENTS FOR THE ISSUANCE OF A NONHOSPITAL ORDER NOT TO RESUSCI-  
50 TATE FOR HOSPICE AND HOME CARE PATIENTS, SUCH SECOND PHYSICIAN SHALL BE  
51 SELECTED BY THE HOSPICE MEDICAL DIRECTOR OR HOSPICE NURSE COORDINATOR  
52 DESIGNATED BY THE MEDICAL DIRECTOR OR BY THE HOME CARE SERVICES AGENCY  
53 DIRECTOR OF PATIENT CARE SERVICES, AS APPROPRIATE TO THE PATIENT.

54 5. CONSENT BY A PATIENT OR A SURROGATE FOR A PATIENT IN A MENTAL  
55 HYGIENE FACILITY SHALL BE GOVERNED BY ARTICLE TWENTY-NINE-B OF THIS  
56 CHAPTER.

1 S 2994-DD. MANAGING A NONHOSPITAL ORDER NOT TO RESUSCITATE. 1. THE  
2 ATTENDING PHYSICIAN SHALL RECORD THE ISSUANCE OF A NONHOSPITAL ORDER NOT  
3 TO RESUSCITATE IN THE PATIENT'S MEDICAL RECORD.

4 2. A NONHOSPITAL ORDER NOT TO RESUSCITATE SHALL BE ISSUED UPON A STAN-  
5 DARD FORM PRESCRIBED BY THE COMMISSIONER. THE COMMISSIONER SHALL ALSO  
6 DEVELOP A STANDARD BRACELET THAT MAY BE WORN BY A PATIENT WITH A NONHOS-  
7 PITAL ORDER NOT TO RESUSCITATE TO IDENTIFY THAT STATUS; PROVIDED, HOWEV-  
8 ER, THAT NO PERSON MAY REQUIRE A PATIENT TO WEAR SUCH A BRACELET AND  
9 THAT NO PERSON MAY REQUIRE A PATIENT TO WEAR SUCH A BRACELET AS A CONDI-  
10 TION FOR HONORING A NONHOSPITAL ORDER NOT TO RESUSCITATE OR FOR PROVID-  
11 ING HEALTH CARE SERVICES.

12 3. AN ATTENDING PHYSICIAN WHO HAS ISSUED A NONHOSPITAL ORDER NOT TO  
13 RESUSCITATE, AND WHO TRANSFERS CARE OF THE PATIENT TO ANOTHER PHYSICIAN,  
14 SHALL INFORM THE PHYSICIAN OF THE ORDER.

15 4. FOR EACH PATIENT FOR WHOM A NONHOSPITAL ORDER NOT TO RESUSCITATE  
16 HAS BEEN ISSUED, THE ATTENDING PHYSICIAN SHALL REVIEW WHETHER THE ORDER  
17 IS STILL APPROPRIATE IN LIGHT OF THE PATIENT'S CONDITION EACH TIME HE OR  
18 SHE EXAMINES THE PATIENT, WHETHER IN THE HOSPITAL OR ELSEWHERE, BUT AT  
19 LEAST EVERY NINETY DAYS, PROVIDED THAT THE REVIEW NEED NOT OCCUR MORE  
20 THAN ONCE EVERY SEVEN DAYS. THE ATTENDING PHYSICIAN SHALL RECORD THE  
21 REVIEW IN THE PATIENT'S MEDICAL RECORD PROVIDED, HOWEVER, THAT A REGIS-  
22 TERED NURSE WHO PROVIDES DIRECT CARE TO THE PATIENT MAY RECORD THE  
23 REVIEW IN THE MEDICAL RECORD AT THE DIRECTION OF THE PHYSICIAN. IN SUCH  
24 CASE, THE ATTENDING PHYSICIAN SHALL INCLUDE A CONFIRMATION OF THE REVIEW  
25 IN THE PATIENT'S MEDICAL RECORD WITHIN FOURTEEN DAYS OF SUCH REVIEW.  
26 FAILURE TO COMPLY WITH THIS SUBDIVISION SHALL NOT RENDER A NONHOSPITAL  
27 ORDER NOT TO RESUSCITATE INEFFECTIVE.

28 5. A PERSON WHO HAS CONSENTED TO A NONHOSPITAL ORDER NOT TO RESUSCI-  
29 TATE MAY AT ANY TIME REVOKE HIS OR HER CONSENT TO THE ORDER BY ANY ACT  
30 EVIDENCING A SPECIFIC INTENT TO REVOKE SUCH CONSENT. ANY HEALTH CARE  
31 PROFESSIONAL INFORMED OF A REVOCATION OF CONSENT TO A NONHOSPITAL ORDER  
32 NOT TO RESUSCITATE SHALL NOTIFY THE ATTENDING PHYSICIAN OF THE REVOCA-  
33 TION. AN ATTENDING PHYSICIAN WHO IS INFORMED THAT A NONHOSPITAL ORDER  
34 NOT TO RESUSCITATE HAS BEEN REVOKED SHALL RECORD THE REVOCATION IN THE  
35 PATIENT'S MEDICAL RECORD, CANCEL THE ORDER AND MAKE DILIGENT EFFORTS TO  
36 RETRIEVE THE FORM ISSUING THE ORDER, AND THE STANDARD BRACELET, IF ANY.

37 S 2994-EE. OBLIGATION TO HONOR A NONHOSPITAL ORDER NOT TO RESUSCITATE.  
38 EMERGENCY MEDICAL SERVICES PERSONNEL OR HOSPITAL EMERGENCY SERVICES  
39 PERSONNEL WHO ARE PROVIDED WITH A NONHOSPITAL ORDER NOT TO RESUSCITATE,  
40 OR WHO IDENTIFY THE STANDARD BRACELET ON THE PATIENT'S BODY, SHALL  
41 COMPLY WITH THE TERMS OF SUCH ORDER; PROVIDED, HOWEVER, THAT:

42 1. EMERGENCY MEDICAL SERVICES PERSONNEL OR HOSPITAL EMERGENCY SERVICES  
43 PERSONNEL MAY DISREGARD THE ORDER IF:

44 (A) THEY BELIEVE IN GOOD FAITH THAT CONSENT TO THE ORDER HAS BEEN  
45 REVOKED, OR THAT THE ORDER HAS BEEN CANCELLED; OR

46 (B) FAMILY MEMBERS OR OTHERS ON THE SCENE, EXCLUDING SUCH PERSONNEL,  
47 OBJECT TO THE ORDER AND PHYSICAL CONFRONTATION APPEARS LIKELY; AND

48 2. HOSPITAL EMERGENCY SERVICES PHYSICIANS MAY DIRECT THAT THE ORDER BE  
49 DISREGARDED IF OTHER SIGNIFICANT AND EXCEPTIONAL MEDICAL CIRCUMSTANCES  
50 WARRANT DISREGARDING THE ORDER.

51 S 2994-FF. INTERINSTITUTIONAL TRANSFER. IF A PATIENT WITH A NONHOSPI-  
52 TAL ORDER NOT TO RESUSCITATE IS ADMITTED TO A HOSPITAL, THE ORDER SHALL  
53 BE TREATED AS AN ORDER NOT TO RESUSCITATE FOR A PATIENT TRANSFERRED FROM  
54 ANOTHER HOSPITAL, AND SHALL BE GOVERNED BY ARTICLE TWENTY-NINE-CC OF  
55 THIS CHAPTER, EXCEPT THAT ANY SUCH ORDER FOR A PATIENT ADMITTED TO A

1 MENTAL HYGIENE FACILITY SHALL BE GOVERNED BY ARTICLE TWENTY-NINE-B OF  
2 THIS CHAPTER.

3 S 2994-GG. IMMUNITY. NO PERSON SHALL BE SUBJECTED TO CRIMINAL PROSE-  
4 CUTION OR CIVIL LIABILITY, OR BE DEEMED TO HAVE ENGAGED IN UNPROFES-  
5 SIONAL CONDUCT, FOR HONORING REASONABLY AND IN GOOD FAITH PURSUANT TO  
6 THIS SECTION A NONHOSPITAL ORDER NOT TO RESUSCITATE, FOR DISREGARDING A  
7 NONHOSPITAL ORDER PURSUANT TO SECTION TWENTY-NINE HUNDRED NINETY-FOUR-EE  
8 OF THIS ARTICLE, OR FOR OTHER ACTIONS TAKEN REASONABLY AND IN GOOD FAITH  
9 PURSUANT TO THIS SECTION.

10 S 3. The article heading of article 29-B of the public health law, as  
11 added by chapter 818 of the laws of 1987, is amended to read as follows:

12 ORDERS NOT TO RESUSCITATE FOR RESIDENTS OF MENTAL HYGIENE  
13 FACILITIES

14 S 4. Subdivisions 7, 10, 13 and 16 of section 2961 of the public  
15 health law are REPEALED.

16 S 5. Subdivisions 2, 4, 5, 9 and 19 of section 2961 of the public  
17 health law, subdivisions 2 and 19 as amended and subdivision 9 as renum-  
18 bered by chapter 370 of the laws of 1991 and subdivisions 4, 5 and 9 as  
19 added by chapter 818 of the laws of 1987, are amended to read as  
20 follows:

21 2. "Attending physician" means the physician selected by or assigned  
22 to a patient in a hospital [or, for the purpose of provisions herein  
23 governing nonhospital orders not to resuscitate, a patient not in a  
24 hospital,] who has primary responsibility for the treatment and care of  
25 the patient. Where more than one physician shares such responsibility,  
26 any such physician may act as the attending physician pursuant to this  
27 article.

28 4. "Cardiopulmonary resuscitation" means measures[, as specified in  
29 regulations promulgated by the commissioner,] to restore cardiac func-  
30 tion or to support ventilation in the event of a cardiac or respiratory  
31 arrest. Cardiopulmonary resuscitation shall not include measures to  
32 improve ventilation and cardiac functions in the absence of an arrest.

33 5. "Close RELATIVE OR CLOSE friend" means any person, eighteen years  
34 of age or older, who [presents an affidavit to an attending physician  
35 stating that he] is a [close] RELATIVE OR friend of the patient, REGARD-  
36 LESS OF BLOOD OR LEGAL RELATIONSHIP, and [that he] WHO has maintained  
37 such regular contact with the patient as to be familiar with the  
38 patient's activities, health, and religious or moral beliefs [and stat-  
39 ing the facts and circumstances that demonstrate such familiarity].

40 9. "Hospital" means [a general hospital as defined in subdivision ten  
41 of section twenty-eight hundred one of this chapter and a residential  
42 health care facility as defined in subdivision three of section twenty-  
43 eight hundred one of this chapter or] a hospital as defined in subdivi-  
44 sion ten of section 1.03 of the mental hygiene law or a school named in  
45 section 13.17 of the mental hygiene law.

46 19. "Patient" means a person admitted to a hospital [or, for the  
47 purpose of provisions herein governing nonhospital orders not to resus-  
48 citate, a person who has or may be issued a nonhospital order not to  
49 resuscitate].

50 S 6. Section 2961 of the public health law is amended by adding a new  
51 subdivision 6-a to read as follows:

52 6-A. "DOMESTIC PARTNER" MEANS A PERSON WHO, WITH RESPECT TO ANOTHER  
53 PERSON:

54 (A) IS FORMALLY A PARTY IN A DOMESTIC PARTNERSHIP OR SIMILAR RELATION-  
55 SHIP WITH THE OTHER PERSON, ENTERED INTO PURSUANT TO THE LAWS OF THE  
56 UNITED STATES OR OF ANY STATE, LOCAL OR FOREIGN JURISDICTION, OR REGIS-

1 TERED AS THE DOMESTIC PARTNER OF THE OTHER PERSON WITH ANY REGISTRY  
2 MAINTAINED BY THE EMPLOYER OF EITHER PARTY OR ANY STATE, MUNICIPALITY,  
3 OR FOREIGN JURISDICTION; OR

4 (B) IS FORMALLY RECOGNIZED AS A BENEFICIARY OR COVERED PERSON UNDER  
5 THE OTHER PERSON'S EMPLOYMENT BENEFITS OR HEALTH INSURANCE; OR

6 (C) IS DEPENDENT OR MUTUALLY INTERDEPENDENT ON THE OTHER PERSON FOR  
7 SUPPORT, AS EVIDENCED BY THE TOTALITY OF THE CIRCUMSTANCES INDICATING A  
8 MUTUAL INTENT TO BE DOMESTIC PARTNERS INCLUDING BUT NOT LIMITED TO:  
9 COMMON OWNERSHIP OR JOINT LEASING OF REAL OR PERSONAL PROPERTY; COMMON  
10 HOUSEHOLDING, SHARED INCOME OR SHARED EXPENSES; CHILDREN IN COMMON;  
11 SIGNS OF INTENT TO MARRY OR BECOME DOMESTIC PARTNERS UNDER PARAGRAPH (A)  
12 OR (B) OF THIS SUBDIVISION; OR THE LENGTH OF THE PERSONAL RELATIONSHIP  
13 OF THE PERSONS.

14 EACH PARTY TO A DOMESTIC PARTNERSHIP SHALL BE CONSIDERED TO BE THE  
15 DOMESTIC PARTNER OF THE OTHER PARTY. "DOMESTIC PARTNER" SHALL NOT  
16 INCLUDE A PERSON WHO IS RELATED TO THE OTHER PERSON BY BLOOD IN A MANNER  
17 THAT WOULD BAR MARRIAGE TO THE OTHER PERSON IN NEW YORK STATE. "DOMESTIC  
18 PARTNER" ALSO SHALL NOT INCLUDE ANY PERSON WHO IS LESS THAN EIGHTEEN  
19 YEARS OF AGE OR WHO IS THE ADOPTED CHILD OF THE OTHER PERSON OR WHO IS  
20 RELATED BY BLOOD IN A MANNER THAT WOULD BAR MARRIAGE IN NEW YORK STATE  
21 TO A PERSON WHO IS THE LAWFUL SPOUSE OF THE OTHER PERSON.

22 S 7. Subdivision 1, paragraph (b) of subdivision 3 and subdivision 4  
23 of section 2963 of the public health law, subdivisions 1 and 4 as added  
24 by chapter 818 of the laws of 1987 and paragraph (b) of subdivision 3 as  
25 amended by chapter 23 of the laws of 1994, are amended to read as  
26 follows:

27 1. Every adult shall be presumed to have the capacity to make a deci-  
28 sion regarding cardiopulmonary resuscitation unless determined otherwise  
29 pursuant to this section or pursuant to a court order[. A lack of capac-  
30 ity shall not be presumed from the fact that a committee of the property  
31 or conservator has been appointed for the adult pursuant to article  
32 seventy-seven or seventy-eight of the mental hygiene law, or that a  
33 guardian has been appointed pursuant to article seventeen-A of the  
34 surrogate's court procedure act] OR UNLESS A GUARDIAN IS AUTHORIZED TO  
35 DECIDE ABOUT HEALTH CARE FOR THE ADULT PURSUANT TO ARTICLE EIGHTY-ONE OF  
36 THE MENTAL HYGIENE LAW. FOR PURPOSES OF THIS ARTICLE, THE APPOINTMENT OF  
37 A GUARDIAN PURSUANT TO ARTICLE SEVENTEEN-A OF THE SURROGATE'S COURT  
38 PROCEDURE ACT SHALL NOT CREATE ANY PRESUMPTION REGARDING THE PATIENT'S  
39 DECISION-MAKING CAPACITY. THE ATTENDING PHYSICIAN SHALL NOT RELY ON THE  
40 PRESUMPTION STATED IN THIS SUBDIVISION IF CLINICAL INDICIA OF INCAPACITY  
41 ARE PRESENT.

42 (b) If the attending physician [of a patient in a general hospital]  
43 determines that a patient lacks capacity because of mental illness, the  
44 concurring determination required by paragraph (a) of this subdivision  
45 shall be provided by a physician licensed to practice medicine in New  
46 York state, who is a diplomate or eligible to be certified by the Ameri-  
47 can Board of Psychiatry and Neurology or who is certified by the Ameri-  
48 can Osteopathic Board of Neurology and Psychiatry or is eligible to be  
49 certified by that board.

50 4. Notice of a determination that the patient lacks capacity shall  
51 promptly be given (a) to the patient, where there is any indication of  
52 the patient's ability to comprehend such notice, together with a copy of  
53 a statement prepared in accordance with section twenty-nine hundred  
54 seventy-eight of this article, AND (b) to the person on the surrogate  
55 list highest in order of priority listed, when persons in prior subpara-  
56 graphs are not reasonably available[, and (c) if the patient is in or is

1 transferred from a mental hygiene facility, to the facility director].  
2 Nothing in this subdivision shall preclude or require notice to more  
3 than one person on the surrogate list.

4 S 8. Subdivisions 3 and 4 of section 2964 of the public health law  
5 are REPEALED.

6 S 9. Paragraph (a) of subdivision 2 of section 2965 of the public  
7 health law, as added by chapter 818 of the laws of 1987 and subpara-  
8 graphs (i), (ii), (iii), (iv), (v) and (vi) as redesignated and such  
9 subdivision as renumbered by chapter 370 of the laws of 1991, is amended  
10 to read as follows:

11 (a) One person from the following list, to be chosen in order of  
12 priority listed, when persons in the prior [subparagraphs] SUBPARAGRAPHS  
13 are not reasonably available, willing to make a decision regarding issu-  
14 ance of an order not to resuscitate, and competent to make a decision  
15 regarding issuance of an order not to resuscitate, shall have the  
16 authority to act as surrogate on behalf of the patient:

17 (i) a [committee of the person or] GUARDIAN AUTHORIZED TO DECIDE ABOUT  
18 HEALTH CARE PURSUANT TO ARTICLE EIGHTY-ONE OF THE MENTAL HYGIENE LAW OR  
19 a guardian OF A PERSON appointed [pursuant to] UNDER article seventeen-A  
20 of the surrogate's court procedure act, provided that this paragraph  
21 shall not be construed to require the appointment of a [committee of the  
22 person or] guardian for the purpose of making the resuscitation deci-  
23 sion;

24 (ii) the spouse, IF NOT LEGALLY SEPARATED FROM THE PATIENT, OR THE  
25 DOMESTIC PARTNER;

26 (iii) a son or daughter eighteen years of age or older;

27 (iv) a parent;

28 (v) a brother or sister eighteen years of age or older; and

29 (vi) a close RELATIVE OR CLOSE friend.

30 S 10. Paragraph (c) of subdivision 4 and subdivision 5 of section 2965  
31 of the public health law are REPEALED.

32 S 11. Paragraph (d) of subdivision 4 of section 2965 of the public  
33 health law, as added by chapter 818 of the laws of 1987 and such subdi-  
34 vision as renumbered by chapter 370 of the laws of 1991, is amended to  
35 read as follows:

36 [(d)] (C) If the attending physician has actual notice of opposition  
37 to a surrogate's consent to an order not to resuscitate by any person on  
38 the surrogate list[, or, if the patient is in or is transferred from a  
39 mental hygiene facility, by the facility director], the [physician]  
40 PHYSICIAN shall submit the matter to the dispute mediation system and  
41 such order shall not be issued or shall be revoked in accordance with  
42 the provisions of subdivision three of section twenty-nine hundred  
43 seventy-two of this article.

44 S 12. Subdivision 2 of section 2966 of the public health law is  
45 REPEALED.

46 S 13. Paragraph (c) of subdivision 2 of section 2967 of the public  
47 health law is REPEALED.

48 S 14. Subdivision 1 of section 2970 of the public health law, as  
49 amended by chapter 370 of the laws of 1991, is amended to read as  
50 follows:

51 1. For each patient for whom an order not to resuscitate has been  
52 issued, the attending physician shall review the patient's chart to  
53 determine if the order is still appropriate in light of the patient's  
54 condition and shall indicate on the patient's chart that the order has  
55 been reviewed[:]

1 (a) for a patient, excluding outpatients described in paragraph (b) of  
2 this subdivision and alternate level of care patients, in a hospital,  
3 other than a residential health care facility, at least every seven  
4 days;

5 (b) for an outpatient whose order not to resuscitate is effective  
6 while the patient receives care in a hospital, each time the attending  
7 physician examines the patient, whether in the hospital or elsewhere,  
8 provided that the review need not occur more than once every seven days;  
9 and

10 (c) for a patient in a residential health care facility or an alter-  
11 nate level of care patient in a hospital,] each time the patient is  
12 required to be seen by a physician but at least every sixty days.

13 Failure to comply with this subdivision shall not render an order not  
14 to resuscitate ineffective.

15 S 15. Section 2971 of the public health law is amended by adding a new  
16 subdivision 3 to read as follows:

17 3. FOR PURPOSES OF THIS SECTION, AN ORDER NOT TO RESUSCITATE ISSUED BY  
18 A GENERAL HOSPITAL AS DEFINED IN SUBDIVISION TEN OF SECTION TWENTY-EIGHT  
19 HUNDRED ONE OF THIS CHAPTER, OR BY A RESIDENTIAL HEALTH CARE FACILITY AS  
20 DEFINED IN SUBDIVISION THREE OF SECTION TWENTY-EIGHT HUNDRED ONE OF THIS  
21 CHAPTER, SHALL BE DEEMED A HOSPITAL ORDER NOT TO RESUSCITATE.

22 S 16. Subdivision 2 of section 2972 of the public health law, as  
23 amended by chapter 370 of the laws of 1991, is amended to read as  
24 follows:

25 2. The dispute mediation system shall be authorized to mediate any  
26 dispute, including disputes regarding the determination of the patient's  
27 capacity, arising under this article between the patient and an attend-  
28 ing physician or the hospital that is caring for the patient and, if the  
29 patient is a minor, the patient's parent, or among an attending physi-  
30 cian, a parent, non-custodial parent, or legal guardian of a minor  
31 patient, any person on the surrogate list, AND the hospital that is  
32 caring for the patient [and, where the dispute involves a patient who is  
33 in or is transferred from a mental hygiene facility, the facility direc-  
34 tor].

35 S 17. Subdivision 1 of section 2973 of the public health law, as  
36 amended by chapter 577 of the laws of 1993, is amended to read as  
37 follows:

38 1. The patient, an attending physician, a parent, non-custodial  
39 parent, or legal guardian of a minor patient, any person on the surro-  
40 gate list, the hospital that is caring for the patient and[, in disputes  
41 involving a patient who is in or is transferred from a mental hygiene or  
42 correctional facility,] the facility director, may commence a special  
43 proceeding pursuant to article four of the civil practice law and rules,  
44 in a court of competent jurisdiction, with respect to any dispute aris-  
45 ing under this article, except that the decision of a patient not to  
46 consent to issuance of an order not to resuscitate may not be subjected  
47 to judicial review. In any proceeding brought pursuant to this subdivi-  
48 sion challenging a decision regarding issuance of an order not to resus-  
49 citate on the ground that the decision is contrary to the patient's  
50 wishes or best interests, the person or entity challenging the decision  
51 must show, by clear and convincing evidence, that the decision is  
52 contrary to the patient's wishes including consideration of the  
53 patient's religious and moral beliefs, or, in the absence of evidence of  
54 the patient's wishes, that the decision is contrary to the patient's  
55 best interests. In any other proceeding brought pursuant to this subdivi-

1 vision, the court shall make its determination based upon the applicable  
2 substantive standards and procedures set forth in this article.

3 S 18. Section 2977 of the public health law is REPEALED.

4 S 19. Subdivision 1 of section 2978 of the public health law is  
5 REPEALED and subdivision 2, as added by chapter 818 of the laws of 1987,  
6 such section as renumbered by chapter 370 of the laws of 1991, is  
7 amended to read as follows:

8 [2.] The commissioners of mental health and mental retardation and  
9 developmental disabilities[, in consultation with the commissioner of  
10 health,] shall establish such regulations as may be necessary for imple-  
11 mentation of this article with respect to those persons in mental  
12 hygiene facilities.

13 S 20. The opening paragraph of subdivision 1 of section 2979 of the  
14 public health law, as added by chapter 818 of the laws of 1987, such  
15 section as renumbered by chapter 370 of the laws of 1991, is amended to  
16 read as follows:

17 The [commissioner of health, after consultation with the] commission-  
18 ers of mental health and mental retardation and developmental disabili-  
19 ties[,] shall prepare a statement summarizing the rights, duties, and  
20 requirements of this article and shall require that a copy of such  
21 statement:

22 S 21. Subdivisions 3 and 4 of section 2984 of the public health law,  
23 as added by chapter 752 of the laws of 1990, are amended and a new  
24 subdivision 5 is added to read as follows:

25 3. Notwithstanding subdivision two of this section, nothing in this  
26 article shall be construed to require a private hospital to honor an  
27 agent's health care decision that the hospital would not honor if the  
28 decision had been made by the principal because the decision is contrary  
29 to a formally adopted policy of the hospital that is expressly based on  
30 religious beliefs or sincerely held moral convictions central to the  
31 facility's operating principles and the hospital would be permitted by  
32 law to refuse to honor the decision if made by the principal, provided:

33 (a) the hospital has informed the patient or the health care agent of  
34 such policy prior to or upon admission, if reasonably possible; and

35 (b) the patient is transferred promptly to another hospital that is  
36 reasonably accessible under the circumstances and is willing to honor  
37 the agent's decision AND PENDING TRANSFER THE HOSPITAL COMPLIES WITH  
38 SUBDIVISION FIVE OF THIS SECTION. If the agent is unable or unwilling  
39 to arrange such a transfer, the hospital may intervene to facilitate  
40 such a transfer. If such a transfer is not effected, the hospital shall  
41 seek judicial relief IN ACCORDANCE WITH SECTION TWENTY-NINE HUNDRED  
42 NINETY-TWO OF THIS ARTICLE or honor the agent's decision.

43 4. Notwithstanding subdivision two of this section, nothing in this  
44 article shall be construed to require an individual as a health care  
45 provider to honor an agent's health care decision that the individual  
46 would not honor if the decision had been made by the principal because  
47 the decision is contrary to the individual's religious beliefs or  
48 sincerely held moral convictions, provided the individual health care  
49 provider promptly informs the health care agent and the hospital of his  
50 or her refusal to honor the agent's decision. In such event, the hospi-  
51 tal shall promptly transfer responsibility for the patient to another  
52 individual health care provider willing to honor the agent's decision.  
53 The individual health care provider shall cooperate in facilitating such  
54 transfer of the patient AND COMPLY WITH SUBDIVISION FIVE OF THIS  
55 SECTION.

1 5. NOTWITHSTANDING THE PROVISIONS OF THIS SECTION OR SUBDIVISION TWO  
2 OF SECTION TWENTY-NINE HUNDRED EIGHTY-NINE OF THIS ARTICLE, IF AN AGENT  
3 DIRECTS THE PROVISION OF LIFE-SUSTAINING TREATMENT, THE DENIAL OF WHICH  
4 IN REASONABLE MEDICAL JUDGMENT WOULD BE LIKELY TO RESULT IN THE DEATH OF  
5 THE PATIENT, A HOSPITAL OR INDIVIDUAL HEALTH CARE PROVIDER THAT DOES NOT  
6 WISH TO PROVIDE SUCH TREATMENT SHALL NONETHELESS COMPLY WITH THE AGENT'S  
7 DECISION PENDING EITHER TRANSFER OF THE PATIENT TO A WILLING HOSPITAL OR  
8 INDIVIDUAL HEALTH CARE PROVIDER, OR JUDICIAL REVIEW.

9 S 22. Section 2980 of the public health law is amended by adding a new  
10 subdivision 9-a to read as follows:

11 9-A. "LIFE-SUSTAINING TREATMENT" MEANS ANY MEDICAL TREATMENT OR PROCE-  
12 DURE WITHOUT WHICH THE PATIENT WILL DIE WITHIN A RELATIVELY SHORT TIME,  
13 AS DETERMINED BY AN ATTENDING PHYSICIAN TO A REASONABLE DEGREE OF  
14 MEDICAL CERTAINTY.

15 S 23. This act shall take effect on the first of June next succeeding  
16 the year in which it shall have become a law.

## APPENDIX-2: Research and Bibliography

**FROM: NICOLE STARING, RESEARCHER  
SYRACUSE UNIVERSITY, MAXWELL SCHOOL**

**Phase One: Identify NYS cases that tell the story of the importance of the FHDA, exposing cases that highlight aggressive, and unnecessarily burdensome medical treatments. This research will also identify constituency groups that have intervened in medical treatment cases where there is a lack of family decision-making authority.**

---

**Re: FHCDA  
Date: December 29, 2008**

---

I am responsible for the first portion of the research regarding “end of life care request.” This is described as follows: **Phase One** Identify NYS cases that tell the story of the importance of the FHDA, exposing cases that highlight aggressive, and unnecessarily burdensome medical treatments. This research will also identify constituency groups that have intervened in medical treatment cases where there is a lack of family decision-making authority.

One way to consider the Family Health Care Decisions Act (FHCDA) is as analogous (albeit loosely) to intestacy laws. Intestacy laws are only applicable where an individual has not executed a will, or has executed an invalid will. The intestacy scheme is derived by considering available wills and determining how people generally dispose of their property. Similarly, the FHCDA protects an incapacitated person by granting decision-making rights to a person that the incapacitated individual would have chosen. A person can opt out of the scheme easily by enacting a health-care proxy. The FHCDA is the proposed default plan for an incapacitated person, in the event that they become incapacitated and do not have a health care proxy.

I began researching from the website maintained by Dr. Jack Freer at <http://www.familydecisions.org/lal.html>. He maintains a very thorough website, and I found that it was a good place to gain an understanding of the current law, and give me direction for continuing the research. Also, I was able to look through the information at <http://compassionandsupport.org> which I also found helpful in gaining an understanding of the situation. Here is my proposed “game plan” – let me know what you think, and if I’m missing anything...

**Step One:** to determine the state of the relevant case law by examining all available New York State Court decisions. **Note: do you want information on the evolution of the law or the current state of the law? I can easily provide a brief overview, unless it is redundant. It may be relevant or important to include in this part some information about the “clear and convincing” standard.**

Step Two: to compare and contrast the State law with the Act to expose the inadequacy of the current laws, and the need for the Act. **Note: I found a lot of cases that involve minor children and incompetent adults. I am having a little more difficulty finding cases concerning an adult patient and the court has refused to allow a third party to terminate treatment. However, there are cases where the courts allow the third-party decision-maker to do exactly what this legislation proposes after arduous and expensive court proceedings, which I can only assume are extremely emotionally tolling for the entire family. Also, I have found at least one case where even though there is a health care proxy appointed, this person is denied the right to make a decision concerning artificial nutrition and hydration.** ← **How would the Act impact this last situation?**

Step Three: consider the various advocacy groups that are supporting the Act – their relationship to the Act, and to each other.

### **Other thoughts:**

Also, I have read the “Sheila Pouliot” case, where Judge Tormey says, “There is the law, and then there is what is right.” In advocating for the passage of this Act, I should think this is particularly relevant. Not only is he saying this law is wrong, there is also a conscious disregard for the law as it is currently written.

Some strong arguments in favor of the FHCDA -- The FHCDA would eliminate inappropriate legal intervention in the future by replacing New York's current ad hoc scheme with **certainty and efficiency**.

→ *All but two states – New York and Missouri – have adopted laws or procedures that govern health care and end-of-life decisions for individuals who lack decision-making capacity because of illness or injury.* It is essential that the New York State Legislature pass legislation that reflects a more enlightened approach to providing medical care to people who are incapacitated.

→ The Act ensures that incapacitated patients receive the medical care they would have chosen themselves, the bill provides extensive protections of patients' rights throughout the process, beginning with the determination that the patient is in need of a surrogate.

→ The FHCDA prescribes clear procedures for determining when a patient is no longer capable of making decisions regarding his or her medical treatment. To ensure that this determination is free of bias, the procedures require an evaluation by a physician at the treating hospital and by an independent health or social services practitioner.

**Below is a brief sample of the cases I am finding. Please take a look at them and let me know which, if any, are aligned best with the purposes of the Act. I am finding a plethora of cases in NYS involving patients who were *never* competent, which is covered by the HCDA of 2003.**

[Grace Plaza v. Elbaum, 183 A.D.2d 10 \(N.Y. App. Div. 1992\)](#)

In this case, a nursing home accepted a comatose patient who required artificial nutrition and hydration. After the patient had received this treatment for over a year, the patient's husband and conservator, requested that it be withdrawn. The nursing home refused and tried without success to find another nursing home that could comply with the husband's request. The husband refused

to pay fees for the continued treatment and the nursing home filed an action for breach of contract. The Supreme Court denied the nursing home's motion for partial summary judgment on the issue of liability and dismissed the husband's counterclaim for battery. On appeal, the court reversed the decision as to the husband's liability to pay fees and affirmed the decision to dismiss the counterclaim. The court examined the law of New York and other jurisdictions about the circumstances under which withdrawal of life support could be permitted. Absent a court order, the nursing home committed no legal wrong and forfeited no fees by continuing to give life-saving medical treatment over defendant's objections. Medical professionals could not be compelled to engage in conduct that they considered unethical and for which they could be punished.

[In re Westchester County Med. Ctr. ex rel. O'Connor, 72 N.Y.2d 517 \(N.Y. 1988\)](#)

An elderly woman was a hospital patient who, as a result of several strokes, was mentally incompetent and unable to obtain food or drink without medical assistance. The hospital sought to insert a feeding tube, and the patient's children sought to discontinue all such intervention pursuant to her wishes. The court noted that none of the doctors who testified knew the patient before she became incompetent, and knew nothing of her attitudes toward life-sustaining measures. While the patient had made statements with respect to declining artificial life support as to people suffering terminal illnesses, this was not her situation. The patient was not in a coma or vegetative state, but was awake and conscious. On the record, it could not be said that the patient elected to die under such circumstances, and there was not clear and convincing evidence that she had made a firm and settled commitment, while competent, to decline this type of medical assistance.

[In re AB., 196 Misc. 2d 940 \(N.Y. Sup. Ct. 2003\)](#)

The child, who suffered an apparent seizure and never regained consciousness, sustained massive brain damage and remained in a vegetative state. The child could only breathe when she was attached to a mechanical ventilator. The court granted the mother's petition to remove the child from the ventilator. The case differed from other "right to die" cases where patients had earlier expressed a clear view on treatment; because an infant was incapable of expressing treatment preferences, a court had to assess whether withdrawal of life support would serve the patient's best interests. It was undisputed that the child would not derive any benefit from prolonging her life because of her vegetative state and that the child had no quality of life to preserve. Granting the mother's petition was consistent with N.Y. Surr. Ct. Proc. Act Law § 1750-b, which gave guardians of individuals suffering from mental retardation the authority to withhold life-prolonging treatment, as well as with N.Y. Pub. Health Law § 2504(2), which granted parents the right to give effective consent concerning medical services for their children. It was also consistent with American Medical Association guidelines.

[Matter of DH, 2007 NY Slip Op 27075, 1 \(N.Y. Misc. 2007\)](#)

The patient, a fourteen-year-old boy, suffered from Hunter Syndrome, for which there was no known cure and would be fatal within the next two years. The patient was placed on a ventilator to enable him to breathe, trached, in order to stop aspiration, and had a feeding tube inserted into his stomach. The patient's parents testified that they understood that removing the ventilator would hasten the patient's death, but felt that this was in his best interests to end his suffering. The medical ethics committee supported the parents' decision. However, the director of pediatric critical care testified that the patient was alert, was not in pain, and could sense his surroundings.

The patient recognized people and enjoyed watching videos. The court was persuaded that the weight of the evidence favored continuing treatment. The patient lacked the capacity to consent to his medical treatment and was suffering from a terminal disease, but the burdens of prolonged life were not so great so as to outweigh any pleasure, emotional enjoyment or other satisfaction that the patient could yet be able to derive from life.

→The court distinguishes this case from *In re AB*; says they are not at all the same situation.

[Borenstein v. Simonson, 2005 NY Slip Op 25135, 1 \(N.Y. Sup. Ct. 2005\)](#)

The sister argued that the patient would have wanted a PEG tube inserted. The daughter refused to allow the insertion of a PEG tube. The trial court held that the individual left no written instructions in her Health Care Proxy as to the administration of artificial nutrition and hydration. The daughter, therefore, was without authority to make decisions on artificial nutrition and hydration. The sister's request to revoke the Health Care Proxy was rejected as the individual was competent when she executed the Proxy. The daughter did not act in bad faith in refusing to allow the PEG tube, even though it was recommended by all of the treating physicians, as the trial court was not convinced that the PEG tube was in accordance with the individual's religious and moral beliefs. The daughter could technically render future decisions as to the individual's medical treatment, other than artificial nutrition and hydration decisions, without consulting the sister. The treating physicians were technically mandated to provide the individual with artificial nutrition and hydration, without consulting the daughter. However, ideally, the family would resolve their differences.

---

**Re: NYS Assembly Legislative Hearing held Dec. 8, 2005**  
**Date: January 30, 2009**

---

Listed below are a list of the names of people who testified and the available contact information I could locate. They did not provide contact information through the hearing; this list represents contact information that is available elsewhere on the internet.

- Carl Coleman, Professor of Law and Director, Health Law and Policy Program, Seton Hall Law School Family Decisions Coalition
  - Email: [colemaca@shu.edu](mailto:colemaca@shu.edu)
  - Phone: (973) 642-8586
- Kathy A. McMahon, President and CEO, Hospice and Palliative Care Association of New York State
  - Email: [kcmcmahon@hpcanys.org](mailto:kcmcmahon@hpcanys.org)
  - Phone: (518) 446-1483
- Diane E. Meier, MD, Director, The Lilian and Benjamin Hertzberg Palliative Care Institute
  - Email: [Diane.meier@mssm.edu](mailto:Diane.meier@mssm.edu)
  - Phone: (800) 637-4624
- David Hoffman, Vice President, Ethics and Compliance and General Counsel, Wyckoff Heights Medical Center

- Katherine Hawkins, MD, Association of the Bar of the City of New York Health Law Committee
- Richard E. Barnes, Executive Director, New York State Catholic Conference
  - Phone: (518) 434-6195
- Elisabeth Benjamin, Director, Reproductive Rights Project, New York Civil Liberties Union
  - Phone: (212) 607-3327
- Lorraine M. Ryan, Esq., Special Counsel, Legal, Regulatory and Professional Affairs, Greater New York Hospital Association
  - Email: [ryan@gnyha.org](mailto:ryan@gnyha.org)
  - Phone: (212) 506-5416
- Barbara Crosier, Vice President, Government Affairs, Cerebral Palsy Association of NYS
  - Email: [AffiliateServices@cpofnys.org](mailto:AffiliateServices@cpofnys.org)
  - Phone: (518) 436-0178
- Nancy D'Agostino, RN, MSN, Administrator, Calvary Hospital Home Care and Hospice
  - Email: [ndagostino@calvaryhospital.org](mailto:ndagostino@calvaryhospital.org)
  - Phone: (718) 518-2465
- Kathy Faber-Langendoen, MD, Director, University Hospital Ethics Consultation Service, SUNY Upstate Medical University
  - Email: [faberlak@upstate.edu](mailto:faberlak@upstate.edu)
- Thomas L. Balch, New York State Right to Life Committee
- Amy Paul, Executive Director, Friends and Relatives of Institutionalized Aged, Inc.
  - Email: [fria@fria.org](mailto:fria@fria.org)
  - Phone: (212) 732-4455
- Carl Young, President, New York Association of Homes and Services for the Aging
  - Phone: (518) 449-2707 ext. 120
- David Zwiebel, Esq., Executive Vice President for Government and Public Affairs, Agudath Israel of America
- Susan M. Cohen, Chair, New York State Breast Cancer Network
  - Email: [info@nysbcnsen.org](mailto:info@nysbcnsen.org)
- Robert N. Swidler, General Counsel of Northeast Health, NYS Bar Association Health Law Section
  - Email: [swidlerr@nehealth.com](mailto:swidlerr@nehealth.com) (w); [rswidler@aol.com](mailto:rswidler@aol.com) (h)
  - Phone: (518) 271-5027
- Kathleen M. Burke, Esq. Vice President, Secretary and Counsel, New York Presbyterian/Weill Cornell, NYS Bar Association Health Law Section
  - Email: [kburke@nyp.org](mailto:kburke@nyp.org)
- Allen J. Bennett, MD, Chair, Medical Ethics Committee, Medical Society of the State of New York
- Ben Golden, Director, Governmental Affairs, NYSARC, Inc.
  - Email: [goldenb@nysarc.org](mailto:goldenb@nysarc.org)
  - Phone: (518) 439-8311 ext. 207
- Rabbi David Kaye, Director, Department of Pastoral Services, Chair, Medical Ethics, Parker Jewish Institute for Health Care and Rehabilitation
  - Phone: (718) 289-2279

- Sonia Ossorio, President, New York City Chapter, National Organization for Women
  - Phone: (212) 627-9895
- Peter Sarver, Lutheran Statewide Advocacy
- Charles Archer, Esq., Associate Executive Director, InterAgency Council

The following organizations support the Family Health Care Decisions Act. They are imbedded as hyperlinks and are also available at [www.familydecisions.org/fhcda-org.html](http://www.familydecisions.org/fhcda-org.html).

### ***Health Care Providers and Medical Organizations***

- [American Cancer Society](#)
- [New York State Association of Homes and Services to the Aging](#)
- [Hospice and Palliative Care Association of New York State](#)
- [New York Academy of Medicine](#)
- [New York State Association of Health Care Providers](#)
- [New York State Health Facilities Association](#)
- [New York State Nurses Association](#)
- [Western New York Ethics Committee Network \(UB Center for Clinical Ethics\)](#)
- [Healthcare Association of New York State](#)
- [Medical Society of the State of New York](#)
- [1199 SEIU United Healthcare Workers East](#)
- [Visiting Nurse Service of New York \(VNS\)](#)

### ***Civic and Religious Organizations***

- [Association of African-American Gerontologists](#)
- [American Jewish Congress](#)
- [Association of the Bar of New York City](#)
- [New York State Bar Association-Health Committee](#)
- [Lutheran Statewide Advocacy](#)
- [Older Women's League \(OWL\)](#)
- [New York State Community of Churches \(formerly: Council of Churches\)](#)
- [Women's City Club](#)
- [Temple Sinai, Buffalo](#)
- [Retirees Association of DC 37](#)

### ***Patients' Rights Organizations***

- [Coalition of New York State Alzheimer's Association Chapters](#)
- [Cancer Care](#)
- [Institute for Puerto Rican/ Hispanic Elderly](#)
- [Coalition of Institutionalized Aged and Disabled](#)
- [Center for Medical Consumers](#)
- [Consumers Union](#)
- [Friends & Relatives of the Institutionalized Aged \(FRIA\)](#)
- [NYSARC, Inc. \(Formerly the New York State Association for Retarded Children\)](#)
- [New York Citizens Committee on Health Care Decisions](#)

- [Long Term Care Community Coalition](#)
- [New York Civil Liberties Union](#) and [NYCLU's FHCDA support page](#)
- [Nursing Home Community Coalition of New York State](#)
- [Last Acts Partnership](#)
- [Nassau County Long Term Care Ombudservice](#)
- [New York City Substate Long- Term Care Ombudservice](#)
- [NY Statewide Senior Action Council](#)
- [Disabled in Action of Metropolitan New York](#)
- [JPAC for Older Adults](#)
- [Spanish Speaking Elderly Council-RAICES](#)
- [Save Our Services on Long Island \(SOS-LI\)](#)
- [Suffolk County Long Term Care Ombudservice](#)
- [Westchester Health Action Coalition](#)

---

**Re: FHCDA; Opposition**  
**Date: March 9, 2009**

---

1. David Zweibel, Agudath Israel of America. This is a national Orthodox Jewish organization with headquarters in New York.
  - a. This organization also originally testified in 1995, but there is no indication of how they felt at that time.
  - b. At page 290, “We are constrained to express our opposition to the bill despite the fact that there are several aspects of this legislation which we believe are extremely favorable and positive features.”
    - i. This organization is particularly pleased that when conferring certain decision-making authority upon surrogate decision makers, there is very clear guidance that the surrogate decision maker do so in a manner which takes into account the patient’s wishes, and specifically spells out that the patient’s religious beliefs be considered.
  - c. At 292, he reiterates, “It is particularly painful for me to say that our organization opposes this legislation in its current form.”
    - i. Their position – currently the law in New York is that where there is no clear and convincing evidence of what a patient’s wishes would have been then resolve all doubts in favor of life. This means that if you don’t know for certain that the patient would have wanted then assume the patient should be kept alive. This organization believes this is a “correct, wish and judicious approach toward this very difficult and very sensitive set of issues.”
    - ii. Under the “new bill” the surrogate decision-maker (who wasn’t actually appointed by the patient) is empowered, in situations where there is no clarity in terms of the patient’s wishes about having nutrition and hydration continued, to end the life-sustaining treatment.
      1. The step away from the “clear and convincing evidence” standard is the problem for this group.

2. They want to have it both ways, they want the decision-maker to have the latitude to make well-informed decisions, but they do not want the decision-maker to have the freedom to make healthcare decisions absent this rigorous standard of proof.
  - iii. He closes his piece by saying, “I certainly believe that the clear and convincing evidence standard, which resolves questions of that in the area of preservation of life, is something that we can be proud of and should maintain.” (at pg. 297).
2. Recall that Rabbi David Kaye, Director of the Department of Pastoral Services, and the Chair of Medical Ethics for the Parker Jewish Institute for Health care and Rehabilitation, strongly supports this legislation.
  - a. I think this is an important distinction between the two people, and it is telling. The Rabbi who works with the suffering and their families thinks this legislation is good and is able to reconcile the language in the legislation in favor of the Jewish faith, not in opposition to it.
3. Assemblyman O’Donnell did not outright oppose the bill. However, he was concerned about the lack of a “priority list” especially as this could relate to domestic partners and surrogate decision-making. His main concern was that without a list that specifically referenced domestic partners, specifically homosexuals, then these couples would be overlooked in the surrogate decision-making capacity.
4. Sonia Ossorio, National Women’s Organization
  - a. This group would like to see the bill have a prioritized list that includes a partner at the same level as a spouse. There is no room for compromise on this issue, and the suggested definition for domestic partner should mirror the definition laid out in the hospital visitation bill.
  - b. The second concern is with the “pregnant patient clause.” This group thinks it is unnecessary and potentially dangerous. She describes the clause as “a sleeping giant.” The fear is that in trying to get fetal rights, a woman’s access to choice is undermined.

## Conclusion

The concerns, which lead to opposition, primarily center on the lack of a priority list in the 2005 version, the inclusion of a specific provision protecting a fetus where the mother lacks decision-making capacity, and the concern over giving the surrogate the right to make a decision based on the patient’s wishes when those wishes are unknown.

However, I think it is important to note that *no one outright opposed the entire bill* or the idea of a surrogate decision-maker. The basic premise of the bill – that those closest to the patient, who know what the patient would want, should be the ones making the health care decisions – was universally accepted and applauded. As always, the devil is in the details, and it is what each individual interest group reads into the details that cause the hang-ups.

---

**Re: Final Notes**  
**Date: February 8, 2009**

---

When I started this project, I will admit that I had reservations about the wisdom of a bill that would determine who could make health-care decisions for a person who can no longer make decisions themselves. However, after reading about the Act and the stories of the caregivers, doctors, and families who find themselves in situations where decisions have not been made about end of life care, I believe that this bill is the correct answer to the problem.

The majority of New Yorkers do not have health care proxies or a form of an advance directive. The health care proxy law (Public Health Law art. 29-C) was enacted to fill a void in New York law by “establish[ing] a decision-making process to allow competent adults to appoint an agent to decide about health care treatment in the event they lose decision-making capacity” (NYS L 1990, ch 752, 1). While the health care proxy law is a departure from the common-law prohibition against allowing health care decisions to be made on behalf of an incompetent person based upon the agent's substituted judgment and/or belief as to the incompetent's best interests, **the law is nevertheless premised upon the same policy as the common-law principles--to ensure that an individual's wishes concerning his own health care treatment are followed.** The health care proxy law merely permits a competent individual to express an intention that, in the event of incompetence, he desires that a certain individual be permitted to make health care decisions on his behalf. The Act expressly requires, however, that the principal be competent in the first instance in order to appoint a health care agent (Public Health Law § 2981 (1)).

Research has established that most New Yorkers do not have a health care proxy enacted. Although the health care proxy law was enacted to fill a void, it has left a void as well. According to the results of the Sarah Lawrence College Literacy Study, a majority of the responders chose to have decisions made for them in an order similar to the priority list included in the Family Health Care Decisions Act. Even more striking, most of these people believe that their family will be able to make end of life treatment and care decisions on their behalf.

I think it is very important to remember that this act speaks to the values we are seeking to protect. A third party is going to have to make a decision regarding health care and treatment for a person who becomes incapacitated; currently the doctor is that third party. However, the doctor is bound by his own creed and the creed of the hospital or facility he is working in. The patient may have a contrary creed, belief or desire regarding end of life treatment. The FHCDCA puts in place a rebuttable statutory mechanism for determining who is best able to speak on behalf of a person who is no longer able to speak for themselves, a person who is most likely to know what the incapacitated patient's wishes would have been. The language of the bill protects the relationships that legislature finds difficult to define, such as, close friendships and domestic partners. The primary concern of the act is to determine who can best speak on behalf of a patient's wishes, or who is most likely to know what a patient's wishes would be. This act is crucial to providing the best health care possible to New York residents.

Finally, I think that the current state of the law places physicians, doctors, lawyers, and other medical staff at odds with the law. The law should not come between the ethics of a doctor and the ethics or belief system of a patient. In the legislative hearing, time after time the health care

providers talked about how they were faced with a decision, do what's right or break the law. The failure to allow family members or close friends to act as surrogate decision-makers leaves the doctors' hands tied.

### *My own family experience*

My own family experience with New York State end of life decision-making law is not directly on point, but it does demonstrate the rigid procedures in place. My grandfather had type-II diabetes, and had suffered two heart attacks. He had a weak heart, and was in poor physical health at the end of his life. My uncle, who resides in New Hampshire, was his health care proxy and was in possession of his Do Not Resuscitate papers. My grandfather was in and out of the hospital for the last five years of his life. We almost lost him on more than one of those "visits." As he neared the end of his life, he became increasingly worse. On two separate occasions my grandfather went into cardiac arrest, and was resuscitated because the paperwork for the DNR order was with my uncle in New Hampshire. After the second cardiac arrest he suffered a stroke, and unbeknownst to us, he had a tumor "the size of a baseball" on his brain. The stroke rendered him partially paralyzed, and he was in an extremely weakened condition. He was in a coma for days following the stroke. At the end of his life he was on a respirator, and artificial nutrition and hydration. His esophagus and wind pipe had been badly injured when the tubes were inserted, and when he attempted to pull them out. My grandfather spent the final 6 weeks of his life in and out of consciousness. It was at this time that we knew he was dying. It is a very surreal feeling to watch someone die. I truly cannot describe it.

*I will try to continue to think about my own family situation and provide you with more details. It is a very difficult thing to think about and to write about. At the time I was consumed with grief and the difficulty of handling the loss. It is odd to begin letting go of someone before they are gone. That makes it even more difficult to recall the details of his end of life health care decision-making.*

**FROM: JANE GELBMANN, RESEARCHER  
SYRACUSE UNIVERSITY, MAXWELL SCHOOL**

**Phase Two: Research quality of care at end-of-life as it relates to palliative care verses aggressive therapies including life sustaining medical treatment.**

**Quantitative: Research data on the current experience (and related costs) in NYS related to aggressive, clinical interventions during the last weeks of life such as chemotherapy and burdensome artificial life sustaining treatments.**

**Qualitative: Research on palliative care vs. aggressive medical treatments as it relates to patient-centered care and the respective perceptions of greater quality of life for these patients. Include comparative cost data as may be available.**

---

**Re: Excessive end of life costs  
Date: February 23, 2009**

---

In this memo I have summarized additional data regarding the cost of palliative care versus usual care at the end of life. This data contains some specific central New York data, as well as data from other parts of the United States. I have also located further statistics regarding the patient experience to complement the cost data.

#### New York State Statistics

To compare excessive end of life costs in New York State relative to the rest of the country, I found that among all states and the District of Columbia in 2005, New York led the nation in percent of Medicare deaths occurring within a hospital (37.2%); Utah had the lowest percentage (17.3%).<sup>i</sup> New York state also had the largest number of hospital days per decedent in the last 6 months of life (16.26 days), compared again to Utah at the low end (7.35 days).<sup>ii</sup>

In regards to total health expenditures per capita, New York state ranked fourth (behind the District of Columbia, Massachusetts, and Maine) in 2004 with \$6,535 per person.<sup>iii</sup> New York State was sixth highest when compared to total spending on hospital care, is third highest in spending on nursing home care, and spends the most nationally on home health care.<sup>iv</sup>

#### *An example from a central New York hospital*

Data (2007 report on FY2005/2006) from a local area hospital's palliative care program found that the average length of stay was 26 days. The average cost savings for a patient enrolled in palliative care and discharged alive in 2005 was \$2,965, in 2006 the average savings was \$3,827. The average cost savings for palliative care patients who expired during hospitalization in 2005 and 2006 was \$5,807 and \$14,011 respectively. Coupled with national data expressing increased satisfaction and improved pain management, this financial data suggests that palliative care provides benefits for all parties involved in the health care intervention. The per day cost for a palliative care patient was \$427 in 2005 and \$558 in 2006, compared to \$708 and \$746, respectively for non-palliative care patients. First quarter 2007 data suggested that per day palliative patient costs were \$537, and non-palliative patient daily costs were \$818.

Statistically, the savings were found to be significant when modeled with other patient attributes such as length of stay, diagnosis, and discharge status (if patient expired during hospitalization or was discharged alive). All findings of cost savings were significant at the .01 level; the expected treatment cost of a palliative care patient in 2006 is \$8,814 less than a non-participant.

### Palliative Care Cost Information

A study conducted at an 11 bed palliative care unit (PCU) found that for the 123 patients admitted over a six month period, those with both PCU and non-PCU were associated with a 66% cost reduction overall and a 74% reduction in “other” costs (such as medication and diagnostics) after transfer to the PCU. Patients who died inside the PCU had an associated total cost savings of 57% relative to those who died outside of the PCU.<sup>v</sup> This study compared patients with various characteristics such as age, gender, and type of cancer or disease; in all instances there were cost savings present. Furthermore, the study found that all PCU patients had pain scores measured whereas only 2/3<sup>rds</sup> of non-PCU patients had pain scores measured. All PCU patients were offered chaplain visits compared to only 1/3<sup>rd</sup> of non-PCU patients. In all but one of the control cases, death was predictable upon admission, yet only one patient was offered a hospice consultation.<sup>vi</sup>

This study indicated that there were ample opportunities to reduce the care in nearly every case and that significant cost savings would have resulted. For example, stopping oxygen unless dyspnea was present would have saved a minimum of \$125 per day, stopping megestrol acetate would've saved \$12 per day, and omeprazole would've saved at minimum \$3 per day.<sup>vii</sup>

Similarly, a study of Veterans Administration hospitals found that palliative care (PC) patients were 42 percentage points less likely to be admitted to the intensive care unit than usual care (UC) patients. Also, total direct costs per day were, on average, \$239 lower than UC patients and ancillary costs were \$98 less.<sup>viii</sup> The study concluded that this cost difference is due to increased communication between patients, families, and physicians as well as selection of treatments that result in fewer tests and less use of inappropriate medical care. The findings also indicated that the results were linked with better patient and family satisfaction.<sup>ix</sup>

### Patient and Family Experiences

A study in the Bronx, New York, evaluating 592 consecutive palliative care patients between November 2000 and March 2002 indicated that over 90% of the palliative recommendations were accepted and acted upon by a primary care team, indicating a strong consensus between patients, families, and physicians. Records for 368 patients had data about pain measurement; pain and other symptoms improved for 87% of these patients after the palliative care intervention. This study found that 95% of family members surveyed reported that they would recommend the service to others.<sup>x</sup>

This study found that the mean charges for imaging pre-palliative intervention were \$2875, and the mean post-intervention was \$392; comparatively the control group mean “post-intervention” cost (measured from the time the intervention would have taken place) was \$487.62 for the same time period. The mean laboratory tests pre and post-intervention were \$6944.08 and \$1189.86 respectively for the case group and \$5949.19 and \$2200.53 respectively for the control group; this represents a \$5754.22 reduction for the case group and a \$3748.66 reduction for the control group.<sup>xi</sup>

---

<sup>i</sup> Dartmouth Atlas, <http://www.dartmouthatlas.org/>

<sup>ii</sup> Ibid

<sup>iii</sup> Kaiser Family Foundation (2007) *Health Care Expenditures per Capita by State of Residence, 2004*, Kaiser Family Foundation

<http://www.statehealthfacts.org/comparemaptable.jsp?ind=596&cat=5&sub=143&yr=14&typ=4&o=a&sort=n>

<sup>iv</sup> Ibid

<sup>v</sup> Smith, T., et al (2003) *A High Volume Specialist Palliative Care Unit and Team May Reduce In-Hospital End-of-Life Care Costs*, Journal of Palliative Medicine, Volume 6 Number 5, p. 699

<sup>vi</sup> Ibid, p. 700

<sup>vii</sup> Ibid, p. 704

<sup>viii</sup> Penrod, J., et al (2006) *Cost and Utilization Outcomes of Patients Receiving Hospital-Based Palliative Care Consultation*, Journal of Palliative Medicine, Volume 9 Number 4, p. 855

<sup>ix</sup> Ibid, p. 858

<sup>x</sup> O'Mahoney, S., et al (2005) *The Benefits of a Hospital-Based Inpatient Palliative Care Consultation Service: Preliminary Outcome Data*, Journal of Palliative Medicine, Volume 8 Number 5, p. 1033

<sup>xi</sup> Ibid, p. 1038

---

**Re: Palliative Care Findings**

**Date: January 23, 2009**

---

I have been working on Phase 2 of the Research Request to identify quality of care at end-of-life as it relates to palliative care versus aggressive therapies. I have noticed definitional discrepancies among much of the formal literature as to what palliative care consists of; I believe it's necessary to first identify for you the definition of palliative care that I have been working with. The following description seems to be the most widely utilized definition of palliative care:

*Palliative care is the medical specialty focused on relief of the pain and other symptoms of serious illness. The goal is to prevent and ease suffering and to offer patients and their families the best possible quality of life (getpalliativecare.org). Palliative care may be delivered concurrently with life-prolonging medicine and is not prognosis dependent<sup>xi</sup>.*

Between 2000 and 2005, the number of hospitals with palliative care programs grew by 96% and the field of palliative and hospice care was formally recognized as a subspecialty in 2006 by the American Board of Specialties<sup>xi</sup>. Although this specialty is growing rapidly in its utilization, it is still young in terms of its formal organized structure and quantitative data is only recently beginning to accumulate. In order to provide a cohesive picture of the state of palliative care in the United States, I have broken this research into four broad categories: the patient experience, cost comparisons, New York state data, and recent work to establishing palliative care guidelines. Within the patient experience, I have subsections describing patient values, current trends in place of death, and information on wellbeing derived from palliative care.

---

## **The Patient and Family Perspective:**

### ***Values and wishes regarding end-of-life care:***

Numerous studies have found that patients and family members value palliative care and have a more satisfying experience than with the model of care that is usually provided. Patient, family member, and provider wishes reflect a desire for the values that palliative care embodies. A survey of patients, bereaved family members, physicians and other medical personnel, 98% of respondents in all four categories identified “having a decision maker at the end of life” as very important. This study also found that 93% of patients, 95% of family members and 99% of physicians cited “freedom from pain” as very important at the end of life; 86% of patients cited “know that one’s physician is comfortable talking about death and dying as very important.”. Twenty-six items in this study were consistently rated as being important (meaning 70% or more participants indicated an item was important or very important) across all 4 groups of respondents, including 1.) pain and symptom management, 2.) preparation for death, 3.) achieving a sense of completion, 4.) decisions about treatment preferences, and 5.) being treated as a “whole person.” Ten items had broad variation within as well as among the 4 groups, including decisions about life-sustaining treatments, dying at home, and talking about the meaning of death. Participants ranked freedom from pain most important and dying at home least important among 9 major attributes<sup>xi</sup>.

Another study identified similar key values in patients’ perspectives; this study concluded that quality end-of-life care includes 5 domains: 1.) receiving adequate pain and symptom management, 2.) avoiding inappropriate prolongation of dying, 3.) achieving a sense of control, 4.) relieving burden on loved ones, and 5.) strengthening relationships with loved ones<sup>xi</sup>.

In the late 1980s the Robert Wood Johnson Foundation (RWJF) funded a multiyear randomized study of deaths in hospitals. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment’s (SUPPORT) conclusions have been borne out in the work of numerous other clinical and health services researchers and in the results of focus groups and surveys. An essay excerpt from four of RWJF’s senior members explains their findings:

*In its first phase [our] effort showed that hospital care of the dying has severe shortcomings: Americans were dying in pain, were hooked up to machines, and were without a Do Not Resuscitate (DNR) order until the last moment (signifying minimal advance planning). Rarely did patients have an advance directive, and, if they did, it usually was not followed. Little attention was paid to family needs, and the cost of care was high—exhausting many families’ life savings.*

Additionally, a poll conducted and released in mid-March 1999 by the Robert Wood Johnson Foundation displayed Americans attitudes to the current end of life care system. It found that 1.) only about half of Americans think that the health care system does a good or excellent job of involving dying patients and their families in major decisions about their care, 2.) only about half believe that comfort and pain control are good or excellent, 3.) fewer than 40 percent believe that the system does a good or excellent job of preserving patient dignity, and 4.) only 15 percent believe that the system protects family savings from high health costs<sup>xi</sup>.

---

## *Place of death*

The United States has been experiencing a shift regarding the place of death. Trends in national data regarding place of death from 1980 to 1998 found that during these years the percentage of Americans dying as hospital inpatients decreased from approximately 54 percent to 41 percent. In the Northeast region of the United States specifically, the trend dropped from 56% to 44% during this time period<sup>xi</sup>. This shift and increase in the use of hospice indicates that patients are increasingly forgoing all available medical treatments<sup>xi</sup>. Additionally, about 90 percent of Americans die without cardiopulmonary resuscitation, and the vast majority of deaths in intensive care units (ICUs) occur after medical interventions are withheld or withdrawn. Nationwide, hospices enrolled more than 1.2 million patients in 2005, representing one third of all deaths in the United States.

A survey of family members (or other knowledgeable individuals) of decedents was used to estimate end-of-life care outcomes for deaths from chronic illness in the United States in 2000. Information from death certificates was used to identify participants; informants were asked via telephone about the patient's experience at the last place of care at which the patient spent more than 48 hours<sup>xi</sup>. For 67.1% of decedents the last place of care was an institution; 32.9% died at home, 38.2% did not receive nursing services; 12.5% had home nursing services, and 49.3% had home hospice services. About one quarter of patients in the sample with pain or dyspnea did not receive adequate treatment, and one quarter reported concerns with physician communication. More than one third of respondents cared for by a home health agency, nursing home, or hospital reported insufficient emotional support for the patient and/or 1 or more concerns with family emotional support, compared with about one fifth of those receiving home hospice services.

Furthermore, nursing home residents (68.2%) were less likely than those cared for in a hospital (79.6%) or by home hospice services (96.2%) to always have been treated with respect at the end of life. Family members of patients receiving hospice services were more satisfied with overall quality of care: 70.7% rated care as "excellent" compared with less than 50% of those dying in an institutional setting or with home health services. Of those who spent their last days of care in a hospital, 62.5% had an advance care directive, compared to 81.6% who were home with hospice care. Of individuals reporting that the patient was not always treated with respect, only 3.8% were those with a relation in home hospice, compared to 20.4% who were in hospital or 31.8% who were in nursing home care. Bereaved family members voiced significant concerns with the quality of end-of-life care, regardless of whether care was provided in a nursing home or hospital. Only bereaved family members whose loved one received home hospice services reported higher satisfaction and fewer unmet needs<sup>xi</sup>.

---

## ***Well-being***

The largest study of patients with cancer who received hospice and no chemotherapy versus those who did not receive hospice care but had chemotherapy showed that survival was significantly longer for hospice patients with lung cancer and pancreatic cancer, marginally longer for colon cancer, but no different with breast or prostate cancer. The authors of the study concluded that this was consistent with chemotherapy not prolonging and possibly shortening life for those eligible for hospice. Only a quarter of participants remembered being informed of any treatment options that did not involve chemotherapy, such as palliative care. Evidence, albeit far from conclusive, suggests that concurrent palliative or hospice care alongside routine oncology care improves health outcomes<sup>xi</sup>.

Project Safe Conduct is a collaborative venture between Hospice of the Western Reserve and the Ireland Cancer Center at Case Western Reserve University and University Hospitals of Cleveland, and was one of four winners of the 2002 Circle of Life Award from the American Hospital Association. “Project Safe Conduct exemplifies a successful collaboration between staff at a comprehensive cancer center and a freestanding, community-based hospice in response to a common desire to provide seamless, exemplary patient and family care,”<sup>xi</sup>.

A study of the project’s effectiveness found that before the study, 13% of patients with advanced lung cancer were referred to hospice; afterward, 80% of such patients enrolled in hospices and the average length of stay in hospice increased from 10 days to 44 days. The group with concurrent cancer treatment and palliative care lived slightly longer (not statistically significant), had quality of life preserved longer, used less chemotherapy, and transitioned to hospice enrollment sooner. Additionally, the Dana Farber Cancer Institute conducted a large randomized controlled trial of usual care plus palliative care consultation, in which 27% to 34% of patients had cancer. Participants between the control group and intervention group showed no difference in symptoms or survival but did show a \$4855 per patient cost savings<sup>xi</sup>.

## **Cost of end of life care:**

An analysis of data from eight palliative care programs in the United States between 2002 and 2004 found that palliative patients who were discharged alive had an adjusted net savings of \$1696 in direct costs per admission and \$279 savings in direct costs per day (direct costs are costs that can be attributed to medications, procedures, or services). Palliative care patients who died during this time period had an adjusted net savings of \$4908 in direct costs per admission and \$374 per day<sup>xi</sup>.

A controlled trial of interdisciplinary palliative care services (IPCS) in Denver, Portland, and San Francisco found that participants reported higher quality of care on the Care Experience Scale (IPCS received a 6.9 compared to a score of 6.6 for usual hospital care). Furthermore, IPCS patients had fewer intensive care admissions upon hospital readmission compared to usual care (12 vs 21), and a six month net savings of \$4,855 per patient. There were no differences in survival or symptom control<sup>xi</sup>.

---

Of the 2.3 million Americans who died in 1997, roughly 2 million (86%) were on Medicare<sup>xi</sup>. Spending in the last year of life accounted for 27.4 percent of all Medicare outlays for the elderly, similar to the 26.9–30.6 percent range in earlier decades<sup>xi</sup>; the share of Medicare spending for persons in the last year of life has been stable for two decades. Medicare payments in the last year of life are almost 6 times the cost for survivors; overall costs per patient have been increasing (even above the rate of inflation) and end of life care is increasing just as rapidly<sup>xi</sup>.

A 2004 study found that for patients at a comprehensive cancer center referred to palliative care, severe distress on admission and severe symptoms of distress significantly improved after palliative care consultation; concurrently the mean daily charges in the patient care information system were 38% lower than the mean daily charges for the rest of the hospital<sup>xi</sup>.

### **Palliative Care in New York:**

The Center to Advance Palliative Care state by state report card on access to palliative care gave New York a grade of “C”, along with the nation as a whole. Only 3 states earned an “A” (Montana, New Hampshire, and Vermont). 70 of 121 (57%) of New York’s hospitals with 50 or more beds have a palliative care program. Nationally, 53 percent of hospitals with fifty or more beds have a palliative care program<sup>xi</sup>.

Data on Syracuse hospitals from the Dartmouth Atlas shows that 26.9% of Medicare enrolled decedents saw 10 or more physicians in the last six months of life. Specifically, Syracuse Medicare decedents between 2001-2005 saw, on average, 7.2 physicians in the last six months of life<sup>xi</sup>.

I also looked at the Dartmouth Atlas Hospital Care Intensity (HCI) index. The HCI measures the propensity of providers to rely on the acute care hospital in managing chronic illness and reflects both the amount of time spent in hospital and the intensity of physician services delivered in the hospital. Patients living in states and regions with a high HCI score are likely to spend more days in the hospital and see more physicians during hospitalizations. New York state ranks as the 2<sup>nd</sup> most aggressive in utilization of services on the HCI Index (New Jersey is first) of all 50 states<sup>xi</sup>.

According to New York State regional data regarding Medicare patients, Elmira area hospitals rank 82.9 (on a scale of 1 to 100) on the HCI index, Albany area hospitals rank 72.1, Buffalo area hospitals 53.4, Syracuse area hospitals 49.1, and Rochester area hospitals 33.7. Within Syracuse area hospitals, those who ranked highest on the HCI index also had a lower percentage of patients enrolled in hospice care; conversely those hospitals scoring lower in the HCI index had higher hospice enrollee percentages.

---

## **Creating Guidelines for Palliative Care:**

Throughout my research I found several mentions of a need to create guidelines at individual institutions for when and how to incorporate palliative care decisions into the patient care process. There has also been some work done to create broader inter-institutional guidelines.

The National Quality Forum (NQF) with support from the Robert Wood Johnson Foundation and the Department of Veterans Affairs, has endorsed a framework to guide the selection of a comprehensive measure set and a set of preferred practices related to palliative and hospice care. Also identified are areas where research is required to fill the gaps in a measurement system (RWJF). In order to ensure that palliative care and hospice services are of the highest quality, NQF envisions a quality measurement and reporting system focused on these critical areas. In addition to initiating a quality reporting and measurement system, the NQF Consensus Report has identified a list of 38 preferred practices for palliative and hospice care<sup>xi</sup>.

Additionally, models for palliative care have been discussed for specialties such as pediatrics<sup>xi</sup>, cardiology<sup>xi</sup>, and has been discussed in regards to ethical treatment of prisoners as well<sup>xi</sup>.

<sup>xi</sup> Kuehn, B. (September 2007) *Hospitals Embrace Palliative Care*, Journal of American Medical Association, Vol 298, No. 11

<sup>xi</sup> Kuehn, B.

<sup>xi</sup> Steinhäuser, K.; Christakis, N.; Clipp, E.; et al. (November 2000) *Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers*, Journal of American Medical Association, <http://jama.ama-assn.org/cgi/content/full/284/19/2476>

<sup>xi</sup> Singer, P.; Martin, D.; Kelner, M. (January 1999) *Quality End-of-Life Care: Patients' Perspectives*, Journal of American Medical Association, <http://jama.ama-assn.org/cgi/content/full/281/2/163>

<sup>xi</sup> Weisfield, V.; Miller, D.; Gibson, R.; Schroeder, S. (November/December 2000) *Improving Care At The End Of Life: What Does It Take? The Robert Wood Johnson Foundation explains why it funds end-of-life care projects and what it has learned*, Health Affairs, Volume 19 No. 6

<sup>xi</sup> Flory, J.; Young-Xu Y.; Gurol, I.; Levinsky, N.; Ash A.; and Emanuel, E.; (May/June 2004) *Place Of Death: U.S. Trends Since 1980*, Health Affairs, Volume 23 No. 3

<sup>xi</sup> Hampson, L.; Emanuel, E. (July/August 2005) *The Prognosis For Changes In End-Of-Life Care After The Schiavo Case*, Health Affairs, Volume 24 No. 4

<sup>xi</sup> Teno, J.; Clarridge, B.; Casey, V.; et al. (January 2004) *Family Perspectives on End-of-Life Care at the Last Place of Care*, Journal of the American Medical Association, <http://jama.ama-assn.org/cgi/content/full/291/1/88>

<sup>xi</sup> Teno, et al

<sup>xi</sup> Harrington, S.E.; Smith, T.J.; (June 2008) *The Role of Chemotherapy at the End of Life: "When Is Enough, Enough?"* Journal of American Medical Association, <http://jama.ama-assn.org/cgi/content/full/299/22/2667>

<sup>xi</sup> interview with Pitorek <http://www2.edc.org/lastacts/archives/archivesjuly02/featureinn.asp>

<sup>xi</sup> Harrington, Smith

<sup>xi</sup> Morrison, R.S.; Penrod, J.; Cassel, B.; et al (September 2008) *Cost Savings Associated With US Hospital Palliative Care Consultation Programs*,

<sup>xi</sup> Gade, G.; Venohr, I.; Conner, D.; et al (2008) *Impact of an Inpatient Palliative Care Team: A Randomized Controlled Trial*, Journal of Palliative Medicine, Volume 11 No. 2

<sup>xi</sup> Lorenz, K.; Shugarman, L.; Lynn, J.; (November 2006) *Health Care Policy Issues in End-of-Life Care*, Journal of Palliative Medicine, Volume 9 No. 3

<sup>xi</sup> Hogan, C.; Lunney, J.; Gabel, J.; Lynn, J. (July/August 2001) *Medicare Beneficiaries' Costs Of Care In The Last Year Of Life: End-of-life costs are only slightly higher for persons who died than for survivors with similar characteristics*, Health Affairs, Volume 20 No. 4

- 
- <sup>xi</sup> Lorenz, et al
- <sup>xi</sup> Harrington, Smith
- <sup>xi</sup> Center to Advance Palliative Care <http://www.capc.org/reportcard/>
- <sup>xi</sup> Dartmouth Atlas [http://cecsweb.dartmouth.edu/atlas08/datatools/datatb\\_s1.php](http://cecsweb.dartmouth.edu/atlas08/datatools/datatb_s1.php)
- <sup>xi</sup> HCI index, Dartmouth Atlas [http://cecsweb.dartmouth.edu/atlas08/datatools/hci\\_s1.php](http://cecsweb.dartmouth.edu/atlas08/datatools/hci_s1.php)
- <sup>xi</sup> QUALITY forum, Dartmouth link <http://www.rwjf.org/files/research/txPHreportPUBLIC01-29-07.pdf>
- <sup>xi</sup> Campbell, Amy (2004) *Planning for the End of Life at the Beginning of Life: A Proposed Model for the Integration of Pediatric Palliative and Hospice Services in the Inpatient Setting, Building on an Organizational Ethic*,
- <sup>xi</sup> Pantilat, S.; Steimle, A. (May 2004) *Palliative Care for Patients with Heart Failure*, Journal of American Medical Association, <http://jama.ama-assn.org/cgi/content/full/291/20/2476>
- <sup>xi</sup> Linder, J.; Meyers, F. (August 2007) *Palliative Care for Prison Inmates*, Journal of American Medical Association, <http://jama.ama-assn.org/cgi/content/full/298/8/894>

I consulted: Using Data to Drive Reform [http://www.rwjf.org/files/publications/other/State\\_Initiatives\\_EOL18.pdf](http://www.rwjf.org/files/publications/other/State_Initiatives_EOL18.pdf)

**APPENDIX-3: “Before and After” screen shots of the [www.compassionandsupport.org](http://www.compassionandsupport.org) website as of April 14, 2009**

**Home Page (Before)**

HOME | EN ESPAÑOL | CONTACT

About Us | Resource Directory | Contribute | Legislation | Research & References | News & Events

Compassion and Support  
at the End of Life

Excelsus

Professionals  
FIND OUT MORE

Patients & Families  
FIND OUT MORE

Know your choices, share your wishes.

Advance Care Planning  
LEARN MORE

**Welcome to Compassion and Support**

Individuals facing serious life-threatening illness and approaching death deserve to be treated with dignity, respect and compassion and to receive care that is focused on the individual's goals for care. Families need and deserve to receive support. To achieve their goals, individuals need to plan ahead, know their choices, make sound decisions and share their wishes with their loved ones and health care professionals. This web site aims to educate and empower patients, families, health care and other professionals to accomplish this goal.

**News and Events**

**MOLST Featured on PBS's "Health Link"**  
Feb. 10, 2009, 7:30pm  
Channel 17 in Schenectady - Albany - Troy

**NEW! Revised MOLST FAQs Approved by NYSDOH**

April 16, 2009 is **National Healthcare Decisions Day!**

**Employer Advance Care Planning Campaign Toolkit:**  
>[Order Here](#)

Search This Site

SEARCH

MOLST Training Videos

MOLST Training Center

CCCC Video Preview

View entire Community Conversations on Compassionate Care (CCCC) Videos.

Home | [Patients and Families](#) | [Professionals](#) | [About Us](#) | [Resource Directory](#) | [Contribute](#) | [Legislation](#) | [Research & References](#) | [News & Events](#) | [Contact](#)

Copyright 2007 Compassion and Support | [Privacy](#) | [Terms of Use](#) | [Design by Practis](#)  
Excelsus BlueCross BlueShield is a nonprofit independent licensee of BlueCross, BlueShield Association.

# Home Page (After)



## Patients & Families

[CLICK HERE](#)



## Professionals

[CLICK HERE](#)

[view all videos](#)

Know your choices, share your wishes.



## Advance Care Planning

Learn Five Easy Steps.  
[click here](#)



## Take Action

Advocate for Legislation.  
[click here](#)



## Play MOLST Videos

Learn more about MOLST. [play now](#)



## Find MOLST Trainer

Carry out MOLST education in your area now. [click here](#)



## Use the MOLST Training Center

Apply MOLST training tools. [click here](#)



## Order MOLST Forms

Obtain MOLST forms and educational resources now. [click here](#)

## Welcome to Compassion and Support

Individuals facing serious life-threatening illness and approaching death deserve to be treated with dignity, respect and compassion and to receive care that is focused on the individual's goals for care. Families need and deserve to receive support. To achieve their goals, individuals need to plan ahead, know their choices, make sound decisions and share their wishes with their loved ones and health care professionals. This web site aims to educate and empower patients, families, health care and other professionals to accomplish

## Featured Topics

### NEW! Revised Advance Care Planning Booklet

The Advance Care Planning Booklet has been revised to follow the format of the Five Easy Steps and include information about the MOLST. Print an ACP Booklet by visiting the [Resource Directory - ACP](#).

### MOLST FAQs

Discover updates on the MOLST Program. Read the newly revised and expanded FAQs.

### Community Guidelines on Long Term Feeding Tube Placement

## News and Events

NEW! [CompassionAndSupport](#) has a new look!

National Healthcare Decisions Day is April 16!  
[Find NHDD events in your area!](#)

## Advocacy Page (Before)

### Search This Site

SEARCH

### In This Section

- [NYS Laws and Regulations](#)
- [Advocacy](#)

## Advocacy

### Advocacy is Needed for Pending Legislation

Your help is needed. Please contact your local state senators and assemblymen today. Together, we can make a difference!

#### Family Health Care Decisions Act

New York State is one of only two States that prohibit family members from making health care decisions for incapacitated loved ones. Under current New York law, no one – not even a concerned family member – has the right to make decisions about medical treatment for patients who lack capacity, unless the patient has signed a proxy or left “clear and convincing evidence” of his or her treatment wishes. Unfortunately, many people never sign a proxy or leave “clear and convincing” evidence of their treatment wishes. As a result, some incapacitated patients are denied appropriate treatment, while others are subjected to burdensome, highly invasive treatment that violates their wishes and prolongs their suffering. The Family Health Care Decisions Act would allow family members and others who are closest to the patient to act as surrogates and make decisions regarding medical treatment for a loved one in certain limited situations. The legislation includes numerous safeguards to ensure sound medical treatment and that decisions are made consistent with the patient’s wishes and best interests. Over forty organizations support passage of the Family Health Care Decisions Act, including the NYS Task Force on Life and the Law, patients’ right organizations, health care providers, and civic and religious organizations. The bill has yet to be re-introduced this year, but both Houses are expected to reintroduce it in the near future.

#### Nurse practitioners Signing DNR Orders

This bill – S.598 – would allow nurse practitioners to sign and execute a DNR order on behalf of a patient. The bill passed in the Assembly last year, but did not pass in the Senate (although the bill did advance out of the Senate Health Committee). Currently, only physicians can sign and execute DNR orders. The law should be expanded to allow nurse practitioners – who are often the primary care providers for certain patients – to sign and execute such orders.

[to top](#)

# Advocacy Page (After)

## In This Section

- NYS Laws and Regulations
- Advocacy

**Compassion  
And Support  
Video Library**  
click here



**MOLST  
Training  
Center**



## Advocacy

### Family Health Care Decisions Act

Family Health Care Decisions Act 2009 bill text (S.03164, sponsored by Senator Duane).

New York State is one of only the only states that prohibits family members from making health care decisions for incapacitated loved ones. Under current New York law, no one - not even a concerned family member - has the right to make decisions about medical treatment for patients who lack capacity, unless the patient has signed a health care proxy or left "clear and convincing evidence" of his or her treatment wishes. Unfortunately, many people never complete a health care proxy or leave clear and convincing evidence of their health care treatment wishes. As a result, some incapacitated patients are denied appropriate treatment, while others are subjected to burdensome, highly invasive treatment that violates their wishes and prolongs their suffering.

The Family Health Care Decisions Act (FHCDA) would allow family members and others who are closest to the patient to act as surrogates and make decisions regarding medical treatment for a loved one in certain limited situations. The legislation includes numerous safeguards to ensure sound medical treatment and that decisions are made consistent with the patient's wishes and best interests. Over 100 organizations support the passage of the Family Health Care Decisions Act, as listed on the [NHDD New York State Coalition Collaborators](#) page.

### Take action today!

Let your voice be heard about the importance of enacting FHCDA in 2009! Send this [letter supporting Family Health Care Decisions Act](#) to your New York State legislators. Please feel free to edit the letter as you wish. Search for your [New York State Senators](#), and [New York State Assemblymen](#). [Send your letter to Governor Paterson](#).

### Stories and Testimony

Discover why passage of FHCDA matters to all New York State citizens.

### Read stories of fellow New Yorkers.

- [Mary O'Connor's Story: Defining "Clear and Convincing Evidence"](#)
- [The Doctor with No Health Care Proxy: No One is Immune to New York State Law](#)
- [Mary's Story: No Health Care Proxy... Vulnerable Patients Denied Access to Hospice](#)
- [Mr. B's Story: No Health Care Proxy... Unwanted Futile Treatments May Result](#)
- [Stories from the Family Decisions Coalition](#)

### Read legislative testimony.

- [Dr. Patricia Bomba, 2/13/2009](#)
- [Dr. Jack Freer, 2/20/2009](#)

### Do your Health Care Proxy today!

Be an advocate for yourself and your family. [Follow Five Easy Steps](#).

Special thanks go to the Fellows from the Western New York Community Health Foundation who have assisted in developing this page and identifying the stories of real individuals who would have benefitted from Family Health Care Decisions Act. The Fellows continue to advocate for this critical piece of legislation.

Special Note...

**Batavia News**

A-4 • The Daily News • Thursday, April 9, 2009

**LETTERS TO THE EDITOR**

**Approve Health Care Decision Act**

**Editor:**  
The Family Health Care Decision Act was first introduced in the New York State Legislature in 1994 and still awaits passage. It has been reintroduced this session as Senate Bill No. 03164. While New York State has failed to protect its citizens, 47 other states have enacted similar laws to deal with this complex issue. It would enable family members to act as a surrogate and to decide about treatment for incapacitated loved ones who have not signed a health care proxy. Over 75,000 people die annually in New York

health care institutions and only 20 percent of them have a health care proxy. Most people are also unaware that current law prohibits parents of children over the age of 18 from making health care decisions for their son or daughter if they become incapacitated. The Family Health Care Decision Act provides legal authority for a decision-making system that effectively balances empowerment of a surrogate and adequate protections for an incapacitated patient. The Act specifically establishes procedures for honoring patient wish-

es, while at the same time involving family and loved ones in decision-making for a person unable to make their own health care choices. Please encourage your state representatives to support this important piece of legislation when it is considered again this year so that all citizens of the State of New York receive the protections they deserve. Most importantly, complete a health care proxy and ensure that all members of your family over age 18 have one.  
**Carol L. Mahoney**  
chief executive officer  
HomeCare & Hospice

**EVERYBODY'S COLUMN**

*Buffalo News 1/1*

*4.10.09  
Buffalo News*

**Approve legislation  
on health care proxy**

The Family Health Care Decision Act was first introduced in the State Legislature in 1994 and still awaits passage. It has been reintroduced this session in the Senate. While New York has failed to protect its citizens, 47 other states have enacted similar laws to deal with this complex issue. It would enable family members to act as a surrogate and to decide about treatment for incapacitated loved ones who have not signed a health care proxy.

More than 75,000 people die annually in New York health care institutions, and only 20 percent of them have a health care proxy. Most people are also unaware that current law prohibits parents of chil-

dren over the age of 18 from making health care decisions for their son or daughter if they become incapacitated.

The Family Health Care Decision Act provides legal authority for a decision-making system that effectively balances empowerment of a surrogate and adequate protections for an incapacitated patient. It specifically establishes procedures for honoring patient wishes, while at the same time involving family and loved ones in decision-making.

Please encourage your state representatives to support this important piece of legislation when it is considered again this year so all citizens are protected. Most importantly, complete a health care proxy and ensure that all members of your family over age 18 have one.

**CAROL L. MAHONEY**  
*Chief Executive Officer  
HomeCare & Hospice*

## The Post-Journal

Covering The Way You Live

### Letters To The Editor

> Opinion > Letters To The Editor

Print this Page

[← back to story](#)

#### Support Family Health Care Decision Act

POSTED: April 12, 2009

To the Readers' Forum:

The Family Health Care Decision Act was first introduced in the New York State Legislature in 1994 and still awaits passage. It has been reintroduced this session as Senate Bill #03164. While New York State has failed to protect its citizens, 47 other states have enacted similar laws to deal with this complex issue. It would enable family members to act as a surrogate and to decide about treatment for incapacitated loved ones who have not signed a health care proxy.

Over 75,000 people die annually in New York health care institutions and only 20 percent of them have a health care proxy. Most people are also unaware that current law prohibits parents of children over the age of 18 from making health care decisions for their son or daughter if they become incapacitated.

The Family Health Care Decision Act provides legal authority for a decision-making system that effectively balances empowerment of a surrogate and adequate protections for an incapacitated patient. The Act specifically establishes procedures for honoring patient wishes, while at the same time involving family and loved ones in decision-making for a person unable to make their own health care choices.

Please encourage your state representatives to support this important piece of legislation when it is considered again this year so that all citizens of the State of New York receive the protections they deserve. Most importantly, complete a health care proxy and ensure that all members of your family over age eighteen have one.

Carol L. Mahoney

Chief Executive Officer

HomeCare & Hospice

Deean

# Family Health Care Decision Act long overdue in N.Y.

By Carol L. Mahoney

The Family Health Care Decision Act was first introduced in the New York State Legislature in 1994 and still awaits passage. It has been reintroduced this session as Senate Bill 03164.

While New York state has failed to protect its citizens, 47 other states have enacted similar laws to deal with this complex issue.

If enacted, this law would change the health care standard for all New York citizens. It would enable family members to act as a surrogate and to decide about treatment for incapacitated loved ones who have not signed a health care proxy or left specific oral or written instructions about treatment, such as a living will.

We live in a time when medical technology can extend life well beyond what many would want. Without the legal right to refuse treatment at some point, medical technology can impose

enormous personal burdens and suffering on the very patients technology was intended to aid. Every day in New York state vital health care and treatment decisions are being made by health care providers and other unrelated persons, rather than those closest to the incapacitated patient.

The numbers are staggering. Over 75,000 people die annually in New York health care institutions and only 20 percent of them will have a health care proxy. This means that 60,000 people die in hospitals or nursing homes in our state each year with the high probability of being unable to speak for themselves when it matters most. Current law also prohibits parents of children over the age of 18 from making health care decisions for their son or daughter if they become incapacitated. It is hard to imagine a young person involved in an accident or medical emergency whose own parents are barred by current New York state law from making critical medical decisions because they did not execute a health care proxy after they reached their 18th birthday.

The Family Health Care Decision Act provides legal authority for a decision-making system that effectively balances empowerment of a surrogate and adequate protections for an incapacitated patient. The Act specifically establishes procedures for honoring patient wishes and values involving family and loved ones in decision-making for incapacitated patients. It also ensures safeguards to prevent inappropriate decisions, particularly in cases where the wishes of the patient are unknown and there are no primary advocates involved.

Please encourage your state legislators to support this important piece of legislation when it is reintroduced this year so that all citizens of the state of New York receive the protections they deserve. First and foremost, complete a health care proxy to insure that your wishes are honored, and make certain your loved ones and children over age eighteen do the same.

*(Ms. Mahoney is chief executive officer of HomeCare & Hospice.)*

**Readers'  
turn to  
write**

OLEAN TIMES HERALD 4-8-09