April 15, 2020

The Honorable Ralph D. Gants Chief Justice

Supreme Judicial Court John Adams Courthouse

One Pemberton Square Suite 2500

Boston, MA 02108

Re: Enable Guardians to make timely health care decisions to mitigate unnecessary harm

Dear Chief Justice Gants,

We are writing in response to your letter of March 19, 2020 to the Massachusetts Bar Association and Boston Bar Association, inviting members to propose solutions to immediate problems as we work together as judiciary and bar, and with health care providers and Guardians.

In light of the novel Coronavirus (COVID-19) which has occasioned the declaration of a State of Emergency in the Commonwealth of Massachusetts, Executive Order No. 591: Declaration of a State of Emergency to Respond to COVID-19, we respectfully ask the Supreme Judicial Court to take steps to enable Guardians to make timely and appropriate decisions, in consultation with treating clinicians, regarding an Incapacitated Person’s goals of care, code status and end-of-life treatment, to ensure the Incapacitated Person receives the best possible person-centered care and is not subject to unnecessary harm and suffering.

For high-risk, adult patients with a presumptive or confirmed COVID-19 diagnosis who are suffering from the effects of the virus, our physicians report that time is of the essence to clarify care goals and talk about life-sustaining treatment decisions. It can often be a matter of a few hours, or at most a few days, in which physicians and competent patients, Health Care Agents and Guardians must make critical decisions to deliver vital care.

In our current public health emergency, we understand that significant numbers of Incapacitated Persons are confronting urgent critical care decisions. A Guardian’s involvement is crucial to communicate a patient’s care goals, values and care choices and preferences with the treating physician.

On April 7, 2020 the MA Department of Public Health issued *Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,* to provide guidance for the triage of critically ill patients. What may have been considered extraordinary treatment decisions just weeks ago, now become ordinary treatment decisions relying on attending physicians exercising the highest standard of care and skill of their profession. In order to avoid any potential for inequitable care for adults with an incapacity or disability, Guardians, similar to Health Care Agents, must be able to provide timely advocacy and reasonable decision-making in triage determinations. Prior judicial approval to make decisions and sign a MOLST (Medical Orders for Life-Sustaining Treatment) may not be possible in the best interest of the Incapacitated Person.

Further complicating the situation, stay at home advisory orders and restricted visitation at hospitals and care facilities substantially interfere with the Guardian’s ability to advocate. Telephonic communications with clinicians are often the only possible way to discuss care options, complete planning documents (i.e. MOLST), and make changes to treatment plans and code status. In response to the crisis, the MA Department of Public Health recently updated *Emergency EMS Protocols* to allow patients, Health Care Agents and Guardians to provide verbal consent on a MOLST form, where written consent is not possible. This remedy has greatly helped to remove barriers for physicians and patients, Health Care Agents and Guardians, to initiate proactive planning conversations to make timely and reasonable decisions in order to deliver equitable, high quality person-centered care.

Guardians, often the only advocates for high risk adults, are asking for relief as argued in the attached letter (p. 4). Although emergency hearings for extended authority have helped, the worsening exigent circumstances require further remedies.

Of note, hospitals, long-term care & skilled nursing facilities, hospice and palliative care organizations consistently report it is not uncommon for Incapacitated Persons to die before a court hearing can be held to change code status from full treatments to comfort care treatments, where a physician’s determination that full code treatments offer no hope of recovery and may cause unnecessary harm and prolonged suffering. Further, a full code status patient is not able to die peacefully in a long-term care facility and is transported to a hospital where the patient may be subjected to repeated aggressive resuscitation and intubation while waiting for a court hearing. In the current public health crisis, this also tragically further overburdens already-overloaded emergency departments, making it even harder to provide adequate care to all who come there.

This situation has become untenable in light of the COVID-19 epidemic. Guardians, family members, attorneys, and health care providers across all health care settings are asking for immediate remedies to mitigate the potential harm and empower Guardians to advocate for timely, high quality, equitable care.

Therefore, we propose the following:

1. Where a substituted judgement determination is necessary, but a timely hearing is not possible, all temporary and permanent Guardians properly appointed under M.G.L. c.190B shall have the authority to make reasonable and appropriate decisions, in consultation with treating clinicians, regarding an Incapacitated Person’s goals of care, code status and end-of-life care treatment, and shall have the authority to execute a MOLST form (Medical Orders for Life-Sustaining Treatment), for an Incapacitated Person, when such person has a presumptive or confirmed COVID-19 diagnosis and is suffering from the effects of the virus. To the extent that any such decisions would normally involve a substituted judgment determination, under the present exigent circumstances, such decisions become ordinary medical decision making relying on treating physician’s knowledge and skill in keeping with the highest professional standard to provide the best possible care, and where no reasonable person would choose to engage in contra-indicated medical treatments that would be considered futile, would offer no meaningful hope of recovery in the face of a devastating COVID-19 diagnosis, cause unnecessary harm and suffering, and would be considered cruel and/ or inhumane.

2. If there is no properly appointed Health Care Agent under M.G.L. c.201D, or Guardian properly appointed under M.G.L. c.190B, and the incapacitated person has a presumptive or confirmed COVID-19 diagnosis or is a high-risk person turning 18 years old in need of decision-making, and where a timely hearing is not possible, a temporary and permanent guardianship may be deferred where a health care provider can rely on the informed consent of next of kin or an appointed supported decision-making team as “responsible parties” in making health care decisions on behalf of the incompetent or incapacitated person, in accordance with Chapter 201D, Sec.16 of the General Laws of Massachusetts, which states:

“In those instances that a health care proxy has not been executed, nothing herein shall preclude a health care provider from relying upon the informed consent of responsible parties on behalf of incompetent or incapacitated patients to the extent permitted by law.”

We respectfully ask that the Supreme Judicial Court promulgate a Standing Order, pursuant to its superintendence authority, for the above-mentioned proposals to validly take effect under the laws of the Commonwealth as soon as possible.

Thank you for your consideration. We endorse this letter as members of the statewide MA MOLST Advisory Subcommittee and the Guardianship-MOLST Advisory Committee:

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**David Sontag,** Managing General Counsel; Beth Israel Lahey Health

**Erik Fromme,** MD, Dana-Farber Cancer Center and Ariadne Labs

**Massachusetts Health & Hospital Association,** Leigh Simons Youmans; Erin Liang JD

**Massachusetts Medical Society,** Eric Reines, MD on behalf of Maryanne C. Bombaugh, MD, President

**Massachusetts Senior Care**, Tara Gregorio, President; Helen Magliozzi, Director of Regulatory Affairs

**Hospice & Palliative Care Federation of Massachusetts,** Christine McMichael, Executive Director

**UMass Memorial Health Care**, Jennifer Reidy MD, Palliative Care; Michelle Horrigan, Associate General Counsel, Worcester

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References

*Crisis Standards of Care Planning Guidance for the COVID-19 Pandemic,* April 7, 2020, MA Department of Public Health*,* <https://d279m997dpfwgl.cloudfront.net/wp/2020/04/CSC_April-7_2020.pdf>

*Massachusetts allows Verbal Consent on A MOLST Form*, Emergency Update to Protocol 7.3: Medical Orders for Life Sustaining Treatment (MOLST) and Comfort Care/ Do Not Resuscitate (DNR) Order Verification, effective April 3, 2020.<https://www.mass.gov/info-details/covid-19-guidance-and-directives?mc_cid=ade44468c9&mc_eid=bbb0afd1af#emergency-responders-&-law-enforcement->

Letter from Concerned Guardians

April 1, 2020

We are guardians. Gloria, Raul, Judy, Kevin, David, Sharron, August to name only a few, are our responsibility.

These individuals have no involved family members to advocate for their care needs; they have us.

Each has a different diagnosis that has resulted in their need for a Guardian. Many of these people reside in skilled care facilities. We routinely discuss their care with the staff at the nursing homes where they each reside. We attend quarterly care plan meetings. We ensure they have clothing and personal spending monies. On holidays and birthdays, we bring them gifts. We take calls from medical providers on weekends, in the middle of the night and during our family activities.

We are their voice when they cannot speak for themselves. But sadly, we cannot speak for them now, as we face this pandemic.

Many of us worry, what will happen if they develop symptoms of this virus? They are among the vulnerable population, many with pre-existing conditions that make it unlikely they will recover. How do we ensure, during these times, that we have the ability to make decisions to avoid prolonged suffering or unnecessary medical interventions? How do we ensure they are allowed to pass in the comfort of familiar surrounds with the care team that knows them? Many of us do not presently have the authority to change this person’s code status to DNR/DNI/DNH. What do we do about Augusta, a 106 year old Austrian who survived the Holocaust who now is positive of COVID with no advanced directives in place because she hasn't "actively been dying"...until possibly now?

It is our job to advocate for these individuals, many of whom have already spent years in an undesirable existence, some bed bound and 100% reliant on caregivers. But we fear that there may be significant delays when requesting the authority of the court to enable us to make the best decisions for our Gloria’s and Judy’s.

Please take the steps to ensure we can act as their advocates and make the difficult decisions that we may be asked to make during these uncertain times.

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