

**STATE BAR OF MICHIGAN – 2011 ANNUAL MEETING
DNR DECISIONS FOR THE INCOMPETENT – WHO CHOOSES?**

Below is a summary of the recorded transcript of this special program of the SBM Disabilities Work Group of the Equal Access Initiative. It has been edited to minimize repetition. The audience asked many excellent questions. To facilitate use of the summary, responses to questions have been noted in parentheses closest to the most relevant text of presenters' presentations.

The program was introduced by Gregory Conyers, State Bar of Michigan Director of Diversity.

Gregory Conyers I welcome you to our program on behalf of the Justice Initiatives, a community within the State Bar, as well as the Equal Access Initiative. Our Disabilities Work Group is a part of the Equal Access Initiative. I begin with a brief introduction of my panelists:

The Honorable Milton Mack is a judge for the Wayne County Probate Court and a recipient, just last night, of the Frank Kelley Distinguished Service Award from the State Bar of Michigan. He is also a recipient of the National Treat Award. Judge Mack has been working on issues relating to cognitive disorders and advocating for reforms in Michigan's mental health system for a number of years.

Mark Cody is a senior attorney from the Michigan Protection and Advocacy Services. Mark has represented clients with disabilities focusing largely on civil rights, health care, education, housing and employment.

Dr. Tom Tomlinson is Professor and Director for the Center of Ethics and Humanities and Life Sciences at MSU. Dr. Tomlinson's special interest includes resuscitation decisions and the moral status of patients with diminished consciousness.

Kay Felt is a retired Dykema Gossett attorney. She has specialized over the years in health care practice, and was one of the founders of health care practice group for Dykema Gossett. She has long experience on these issues with respect to disabilities. I am going to let Kay begin our presentation.

Kay Felt

I want to thank all of you for coming, and I particularly want to thank the State Bar for making this opportunity available free of charge to people in the community who have to deal with these issues.

Recognition is due to the people who provide such wonderful service to our Disabilities Work Group. Judy Hershkovitz is our administrative assistant. Judy keeps spurring us on with new ideas. Gregory Conyers is the primary liaison with the Bar and is always looking out for our interest. Candace Crowley, the Director for Outreach, and Janet Welch, the Executive Director, also were enthusiastically in favor of opening this program without charge to the community.

We need to bring to your attention Court form MC70 on which requests can be made for people who have a need for special assistance in the Court. It is amazing how few people, even attorneys, know about this important form. In order to reap the greatest benefit, the form should be submitted to the applicable court as soon as possible. As examples, it takes time to arrange moving court proceedings to a more accessible location for the particular case, or to obtain appropriate interpreters.

Our Disabilities Work Group is a reincarnation of a part of the Open Justice Commission which issued a report in 2001 on the status of persons in Michigan with disabilities in order to access the legal system. You can find that on the State Bar website along with the reports and quarterly newsletters of our Work Group.

We will start with Dr. Tomlinson.

Dr. Tomlinson

How should we make decisions about medical treatment for those persons not capable of deciding for themselves? There can't be a single answer to that question because the circumstances and the nature of peoples' decision-making capacities differ in important ways. I want to compare three categories of incompetent persons.

There are the formerly competent persons for whom we have some evidence regarding their previous values, preferences or goals as to illness and medical treatment. This could be in the form of advance directives, conversations with families or friends, or in any other form that communicates some relevant knowledge about them as individuals. Let's call these persons *The Formerly Competent Acquaintances*.

Second, there are those persons who were formerly competent, but whose previous individual values or preferences are utterly unknown to us. Assume that an elderly person arrives at a nursing home or the hospital already profoundly demented with no advance directive and with no known family or friends, who may have long since died or simply moved away. Call these persons *The Formerly Competent Strangers*.

Third, there are those persons who have never been competent, incapable of adopting or expressing an informed and reasoned attitude towards their condition or towards medical treatment. This group would include those with profound developmental disabilities. It would also include infants and young children. Call this third group *The Never Competent*.

How might these three groups differ with regard to decisions about their medical care? *The Formerly Competent Acquaintances* present us with an ethically simpler problem. Our task will be to make the decisions we have reason to believe they would make for themselves based on whatever we know about their previous values and preferences.

We are aiming to exercise their rights of autonomy, including their rights to refuse treatment. We want to make a "substituted judgment" in the language the law has used. This is ethically safe ground, relatively speaking, so long as our evidence is sufficient. As the evidence for their former preferences becomes so tenuous as to disappear, *The Formerly Competent Acquaintance* becomes *The Formerly Competent Stranger*.

The Formerly Competent Strangers present a special ethical danger that we will unwittingly make decisions about their care that are directly contrary to what they would

have preferred. This is so, even if we make a good faith effort to decide in their best interests, because that determination will be based on our perspective on the various harms and benefits of treatment or no treatment, not the patient's.

Is the danger really so stark? Even if we know nothing about the individual, we may still have a sound basis for imputing certain values and preferences to him. For example, public opinion surveys consistently show that about 95% of us would not want life sustaining treatment in the event we were profoundly unaware of our surroundings or severely demented, and indeed a majority of us say we wouldn't want such treatment even if we were only mildly demented. This means, I think, that if we insist on providing such treatments to *Formerly Competent Strangers*, chances are we are acting contrary to their preferences.

Unfortunately, such attitudes as we might discover among the competent can provide no guidance regarding the care of *The Never Competent* who don't get to participate in those surveys. For them, we are forced to make decisions about their care based on judgments of their best interests: whether the benefits of medical treatment outweigh the harms.

Can we have a sound basis for making these judgments? Well here's one place to start: it is in no one's interest to receive treatment that doesn't work, and it is contrary to anyone's interest if that futile treatment comes with painful or disabling side effects. The medical facts can in many cases determine that our intervention is probably not in an incompetent person's interest, independent of any knowledge of that person's values. This is why many hospitals have futile care policies. But what can we say about treatment that's not futile. Would our assessment of the patient's best interest then be based in our values alone? Would we impose the risk of our values on the patient?

Well, I reject the subjectivism that may be implicit in the argument that my thinking that something is good for me is what makes it good for others. To the contrary, I think we can make some objective judgments independent of knowledge of individual preferences.

For example, severe unremitting pain is bad. So is frustration, rage, embarrassment and many other sorts of negative feelings. The experience of pleasure, love, accomplishment - those are good or feelings like them are good. Then we might go so far as to say that the utter absence of consciousness or the ability to relate at all to other human beings is such a diminished state that it is bad in its nature.

We don't need to use language to gauge whether such sufferings or enjoyments are part of someone's experience, even if profoundly retarded. We have the capacity to read other peoples' minds in their behaviors, their facial expressions and other nonlinguistic windows into their subjective experience. This is why the public guardian who refuses to come see his ward in the ICU so infuriates caregivers. He is refusing to see the evidence for himself.

If, in fact, we can make some objective determinations of the benefits and harms experienced by these persons, then can we assess the net benefits and harms of a proposed treatment without making invidious assumptions about whether disabled lives are worth living, which I regard as the bottom of a slippery slope. I don't want to go there if I can help it.

The question could be: Whether the proposed treatment has a substantial risk of leaving the quality of that patient's experience worse than it is now? This requires that we have inventoried both what the patient currently enjoys and what she currently suffers and then have determined what effect our proposed treatment might have on that balance.

If her enjoyments declined or her sufferings increased as a result, the final question that we are left with is this: Would that justify a decision not to provide that treatment, even if it might substantially prolong her life, although at a diminished quality. Some people might say we could only reach that conclusion if the person would be better off dead because the weight of suffering so profoundly outweighs the benefits of living.

This is I think a very high bar which could only be reached when the individual is experiencing profound and unremitting pain or suffering. Since pain can virtually always be reduced or eliminated by medication or other interventions, this is a standard that could rarely be met. So now my question is: Is there any alternative? I think there may be if we are willing to entertain an analogy – the competent adult refusal of treatment. We must understand a competent adult’s refusal of life saving or life prolonging treatment when the life that would remain for her is one at odds with her core values, her identity. Treatment would undermine that identity and leave something less in her own estimation.

So my question is: Can we use similar language about adults who are developmentally disabled? I think they too may have identities. Even if they are not self-conscious or self-ascribed identities, they have likes and dislikes, favorite activities, favorite people, known family or friends characteristic perks or other personal features that give them their character or their personality. If a life prolonging treatment would threaten loss of that identity, would a decision not to provide it be reasonable and in keeping with that person’s values. I bet you can see what I am trying to do – I am trying somehow to steer judgments about the best interest of *The Never Competent* back into the safe harbor, somehow, of substituted judgment.

So they become decisions for the patient rather than decisions about her. If we can’t do that, we face a stark ethical prospect – deciding whether some sorts of lives are not worth living.

Kay Felt

My task is to give the legal background, especially in Michigan, against which to make decisions of the types and situations that Tom describes.

We really have four (4) compelling state interests on which the courts focus: (1) *Preservation of life*. In many of these cases, a court has quite eloquently said that “when the prospect for future life diminishes, the interest of the state then indeed wanes.” And

so *preservation of life* has to be balanced against what is the likelihood of a good outcome for this patient.

(2) *Prevention of suicide*. There was a recent case in which a couple wanted to stop eating because they had decided that they were very close to the ends of their lives and each had a number of debilitating conditions. The assisted living facility in which they resided said, “You can’t do that – that’s suicide.” They left the facility in order to carry out their wishes. Most of the courts have said that deciding to withhold or withdraw life sustaining treatment does not constitute suicide – it results in the death of the person from the underlying condition that the person suffered.

(3) *Protection of third parties*. There are very few such cases. There may be a few involving pregnant patients. State and federal laws require us to attend to whether or not there can be a birth of a child without life-limiting conditions before withholding or withdrawing life sustaining treatment.

(4) *Protection of the ethical integrity of the medical profession*. We cannot require medical professionals to act contrary to their ethical standards. In some circumstances, we have to find someone whose ethical standards would not be violated. This often happens when there are issues that may impinge on both medical ethics and the religious background or status of the professionals or the institution in which the person is found.

As to *previously competent persons*, the a decision-making test that Tom has alluded to is “substituted judgment.” Our duty is the find out what that person would want if the person could make the decision to resuscitate or not to resuscitate or to withhold or withdraw life sustaining treatment. This is grounded in the concept of informed consent. What would the individual presumably have thought about; what are all the consequences that might happen; what are all the opportunities, the risks, the benefits. This right survives incompetency, so that the decision-making must be carried out even though the individual cannot personally carry out the decision. We look at criteria and evidence

such as prior expressed views. It's helpful if they are in writing. It's helpful if there is an advance directive, or letters, or notes. But one of the sad things about advance directives is that sometimes they are not very helpful and they are frequently limited to circumstances in which a person is terminally ill, in an unremitting coma or in a persistent vegetative state. Those are not the most common conditions we face.

Sometimes people will make statements verbally to caregivers or to family members or to friends. We have to try to interpret those statements. The weight that is to be given to them depends on how remote are they in time; how close, specifically, are they to the situation that we are now facing; and how believable are those statements.

The decision to withhold or withdraw life sustaining care that could result in the death of a person is a particularly difficult one. It must be based on clear and convincing evidence that the individual involved would have wanted that result - that the wishes expressed are about situations that are either like or highly, highly, similar to the one at hand.

The *Martin* case (In re Martin, 450 Mich. 204 (1995)) involved a person injured in an accident who was left paralyzed from the neck down. He could not speak or eat. He could breathe and did not require a ventilator, but he did require a feeding tube for nutrition and hydration. The issue was whether or not Mr. Martin's prior statements had been close enough to the circumstances in which he found himself. He had watched the movie *Brian's Song* (which involved a football player who was paralyzed and ventilator-dependent from an accident on the field). Martin reportedly said, "Well I would never want to be in a situation like that." The court said, "But did that mean that when he was to some degree aware, and in no apparent distress, and certainly not terminally ill that he would have wanted his feeding tube removed and to die what could be a long death?" The court held that his statements were not clear and convincing in these circumstances.

Now we can also look at the person's value system if there are insufficient expressed views. Sometimes the person's religious background will help if we can figure out how closely the person adhered to those religious issues. Sometimes we can look at culture.

Sometimes we can look at more objective criteria with something called the *limited objective standard* where, if the person is terminally ill, permanently unconscious, in a persistent vegetative state, or in great pain or in some similar condition, we can then make a decision that it is in some senses futile to proceed and can decide based on less than clear and convincing evidence as to whether or not treatment should be withheld or terminated (See footnote 15 in the *Martin* case.).

We have been asked some questions on futility and virtual futility. The best definition we have of futility comes from a prior regulation that is no longer in effect involving infants. Treatment that is futile "will not resolve all of the patient's life threatening conditions." Virtual futility is the concept that "there might be some benefit from the treatment in the sense of extending a person's life, but at a great cost, particularly some kind of side effect of the treatment or pain from the treatment that would render it inhumane."

Mark Cody

I just have some quick remarks about the *Martin* case and our involvement in it, and then I will return to the discussion later on after the other speakers have addressed these issues and will give a more robust defense of the position that we took.

Michigan Protection and Advocacy Service is an agency designated by the Governor of the State of Michigan to provide legal representation to people with disabilities. We filed an amicus brief in the Michigan Supreme Court in the *Martin* case. Typically, an amicus brief is filed by an organization that has an interest in the subject of the litigation, but most often has no particular awareness of or particular involvement with the individual involved in the case.

The *Martin* case was somewhat different because we had staff lawyers who met with Mr. Martin, were in the courtroom when decisions were made by the probate court about Mr. Martin's treatment – the withdrawal of treatment for Mr. Martin, and we were subsequently involved during the appeals process. We represented not only the interest of Michigan Protection and Advocacy Services, but six other disability rights organizations, ranging from United Cerebral Palsy to the Autism Society, to The ARC (which was the formerly the Association for Retarded Citizens and represents individuals with cognitive impairment), and so we brought the collective voice of those disability organizations to the Michigan Supreme Court. We urged the court to look at four issues and we set out eight questions for the court to address.

It boiled down to procedural issues about what standard the court should adopt in evaluating these cases; the evidentiary standard was “clear and convincing evidence.” In our judgment, there couldn't just be a preponderance of evidence; the judge would have to be convinced with clear and convincing evidence that the person had expressed a choice.

We also urged two positions with regard to the substantive issue of withdrawal of life support, one in the area of what about the person who has made some prior expression of choice with regard to the withdrawal of life support; we said that had to be by clear and convincing evidence that a choice had been clearly expressed by that individual. The probate court disagreed with our opinion. Ultimately, the Michigan Supreme Court agreed with us.

The second real substantive issue which we urged the court to address: what about individuals who have never been legally competent, have life-long incompetence, are terminally ill or in a persistent vegetative state? What is a proper test for a court to determine whether life sustaining treatment should be withdrawn from such an individual? I appreciate Dr. Tomlinson's analogy to a safe harbor.

In those circumstances when an individual has never been able to express a choice with regard to life sustaining treatment, our position was that the safe harbor is extremely small; it's the size of a row boat not a battle ship, and the court should authorize the withdrawal of life sustaining treatment only under the circumstances where the person is terminally ill, or in a persistent vegetative state or experiencing recurring, unavoidable and severe pain such that the administration of life sustaining treatment would be inhumane.

The court's decision in *Martin* was incomplete because it did not really address that issue. It looked at Mr. Martin's circumstances and concluded, using the "clear and convincing" standard that he had not made an express choice with regard to the withdrawal of life support that should be honored by the court.

In footnote 15, the court said, with regard to individuals who have never been competent, to make an informed choice with regard to life sustaining treatment, "We express no opinion about the proper decision-making standard for patients existing in a persistent vegetative state, who are terminally ill or who are experiencing great pain. If a patient has any of these conditions or conditions of a similar nature, more objective approaches may be necessary or appropriate." I will later discuss why we think our more narrowly defined standard would be the appropriate standard for the court to adopt.

Kay Felt

As to people who were formerly competent, there is the issue of who is to decide? If the individual has appointed a patient advocate, the patient advocate takes priority over everyone else. Otherwise, next-of-kin decide in something of a defined order. If there is a spouse, the spouse ought to be considered first and then other family members in relation to the closeness of their actual relationship to the individual (adult children, adult siblings, parents, aunts, uncles, nephews, nieces and others assuming responsibility for disposition of the individual's body). (In response to a question, it was recognized that it is not always best to go in the exact order of the next-of-kin. There may be more remote relatives who have greater knowledge about the individual's wishes and values than even

adult children who have not seen a parent for many years.) Next-of-kin can even exercise substituted judgment for a mature minor who was mature enough to have discussed such decisions.

It has been held in many cases is that if there is no disagreement between next-of-kin and the medical team, the decision can be carried out without the need to go to court to appoint a guardian. I'm sure that the probate judges should be happy about that because they have no idea of how clogged their courts would be if all of these cases had to go to court.

If there is no patient advocate or close next-of-kin, a guardian must be appointed.

We then turn quickly to the never competent person for whom the decision making test is the "best interest" test. Again, the right to refuse is not lost because of incompetency or youth; those individuals still have the rights to refuse.

Criteria for decision-making were enunciated in a case involving a little girl name Joelle Rosebush (*In re Joelle Rosebush*, 195 Mich. App. 675 (1992)). A bicycle accident left Joelle in a coma from which she did not emerge after many months. The court adopted these criteria: (1) What is the present level of the physical, sensory, emotional and cognitive function of this person? Does she react? Does she express any kind of pleasure? Joelle did not. (2) What is the degree of physical pain resulting from her condition, treatment or termination of her treatment? (3) What would be the degree of humiliation, dependence and loss of dignity resulting from her condition and from her treatment or no treatment? (4) What is the life expectancy or prognosis for recovery with or without the treatment?

The physicians agreed that there was almost no prognosis for Joelle's restoration to a cognitive, sapient state. And then, once again, demonstrating how grounded this is in the concept of informed consent: (5) What are the treatment options, the risks, the side effects, and the benefits of each option. And once again, as noted in both the *Martin* and

Rosebush cases, if you have next-of-kin, there is no need to have a guardian appointed as long as there is agreement with the medical team. If there is disagreement, an independent guardian or a family member can be appointed as a guardian. (In response to a question, it was noted that when the medical team recommends withholding or withdrawal of life-sustaining treatment, there should be an opportunity for the next-of-kin or guardian to have an independent medical team of their own choosing examine the patient and make a recommendation. Editorial Note: A case not discussed in the program (*In the matter of Baby AMB*, [248 Mich. App. 144(2002)]) involved many unrelated issues, but one relevant holding of the court is that a physician's recommendation to withhold or withdraw life-sustaining care should almost always be supported by the medical opinion of experts in the field who do not have any relationship to the treatment team.)

A very troubling circumstance is raised when we have guardians who are not family members and the issue then is whether and under what circumstances a non-family member guardian can request or agree to a do not resuscitate order or to withholding or withdrawing of life sustaining treatment. If at all, as Tom has said, this requires mindful participation with the individual, visitation, assessment of the patient, and use of the criteria in the **Rosebush** case.

Serious questions, of course, are raised when commercial guardians insist on the issuing of DNR orders for mildly demented patients in apparently no distress.

We also have some very concerning issues however as to how some courts have interpreted this question. We now will look to Judge Mack for guidance. Some judges have said that non-family member guardians have no authority to agree to or to request a DNR order or to make a decision to withhold or withdraw life sustaining treatment. That could cause many people to languish for years in a most debilitated state.

We had a case in our office involving a developmentally disabled person with a non-family guardian in Montmorency County (*In the matter of Edith Shirey*, Probate Court for the County of Montmorency, File #98005210-DD (2005)). The court allowed the guardian, a former employee of the State mental health system, who had been the individual's guardian for more than 20 years, to participate in decision-making. The court issued an order that the guardian, in consultation with the medical team and acting on medical advice, could agree to a do not resuscitate order and could even agree to remove the individual who was in a very painful condition from the ICU and not to return her to the ICU in the future. The patient had a huge scoliosis of the spine. Every time she was intubated, her only communications were to cry out. There were no prospects for relief for her condition with or without ICU treatment. They had been able to keep her out of the ICU only for a few weeks over of a period of about 18 months. The court gave the guardian these rights when acting on sound medical advice.

That case referenced a very interesting 1977 Massachusetts case, involving a man named Joseph Saikewicz, a profoundly retarded man who had spent all his life in a state facility (*Superintendent of Belchertown State School & Another v. Joseph Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977)). Mr. Saikewicz had a rare form of cancer. It was likely that his life could be extended by only a few months if he were treated with chemotherapy. He would have to be restrained; he would not understand what was going on; treatment would be painful for him; and there would be debilitating side effects. The court in that case used something of a *blended test*, looking at the characteristics of Mr. Sackiewicz and trying to make some substituted judgment about how this would affect him and then also covering the issues of best interest. The court held that under those circumstances, it would be inhumane to treat him since there was no prospect of significantly ameliorating his condition.

The Montmorency County court also considered The Michigan Do Not Resuscitate Procedure Act in which a competent, adult person who is not in a hospital or nursing care

facility may sign a form or wear an arm band, signifying refusal to accept resuscitation at home or during EMS transport. It does not deal with rights of guardians. The court held that that Act does not apply in a hospital or nursing care facility and does not prohibit a guardian from requesting or acquiescing in do not resuscitate orders or orders to withhold or withdraw life sustaining care in a hospital or a health care facility.

We do have some judges who, I think, reach too far in relying on some provisions of these statutes and decline to allow guardians to request or agree to these decisions.

We are honored to have Judge Mack with us; he has been very helpful to our committee in several contexts over the years.

Judge M. Mack

This is an extraordinarily confusing area of the law. We have four (4) separate statutes that may or may not apply. We have an Attorney General opinion which has been pretty much overblown. We have the *Martin* case which provides some guidance, but the dissent strongly disagrees. I am afraid that I have helped contribute to the confusion in one of my recent opinions. What is remarkable to me is the infrequency with which an issue of this importance is presented to the courts. I have had to address this issue once in 20 years on the bench. I have determined now that I did not correctly analyze the statutes in question, in particular, the Do Not Resuscitate Procedure Act, but fortunately, I got the right result. (In response to a question, Judge Mack said that he could not now reissue the opinion, but intends in other available ways to inform his colleagues of what he now feels were misinterpretations of the several statutes involved. A presentation he made to colleagues in 2012 is linked to a Disabilities Work Group newsletter published in December 2012 on the SBM website.)

There are many probate judges in Michigan now who have widely different opinions on what a guardian can do. This is because of the DNR Act, because of the Attorney General opinion, and because of the *Martin* decision. The opinions are all over the place, and we get this case every 20 years.

So, let's start with the Probate Code, also known as EPIC. It defines what guardians can do, but does not provide real clear guidance to guardians on what to do in these cases. The Patient Advocate Act, part of EPIC, expressly provides the terms and conditions under which a patient advocate may consent to the withdrawal of life saving treatment. So do the differences in these acts mean that guardians don't have the same powers as patient advocates. That's the question.

At the same time, Michigan's Dignified Death Act speaks to the authority of guardians to consent to withholding treatment, but Michigan's Do Not Resuscitate Procedure Act does not. So, I have taken another look at the DNR Act, and now I am convinced, it has absolutely nothing to do with the authority of guardians to consent to DNR orders. In fact, the Act doesn't apply to guardians at all, and that is because there is an obscure section of the statutes located way in the back – all the way in the back of the Act - which says: "The provisions of this Act are cumulative and do not impair or supersede a legal right that a guardian may have to consent to or refuse medical treatment on behalf of another."

In fact, there is that power of a guardian somewhere else. It is in the common law (that body of Anglo-American court decisions that has grown over the centuries).. We sometimes forget about the common law because the law is so statutorily driven these days. So EPIC itself gives us some statutory guidance which is somewhat limited. It basically says that a guardian is responsible for the care, custody and control of the ward and that the guardian *may* give the consent necessary to enable the ward to receive medical care. Implicit in the use of the word *may*, is the right to say no – may not give consent. (In response to a question, Judge Mack commented on the issue of co-guardianship, noting that when there are co-guardians, each must be involved in each decision. Judge Mack and Mark Cody noted that neither favors co-guardianship, and each counsels people against it.)

So, we see cases like this where there is a dispute. So, where does that leave guardians?

I am going to try to give you clear guidance.

First, do guardians have the authority to consent to DNR orders? Answer, Yes. It doesn't matter whether it's a person who never had competence or had competence and lost it; it doesn't matter; guardians have the authority. Think about it like a driver's license. You have a driver's license; you have the authority to drive on our freeways. The guardian has the power.

Number two (2). Is a court order required for a guardian to consent to a DNR order? The Answer, No. If the guardian consults with a treatment team, and it's agreed that an DNR is appropriate and no one objects, we will not see that case, and the team can proceed to act under the guardian's instructions. (It was noted by Judge Mack in response to several questions that a DNR order is a medical order that must be signed by at least one physician, ideally in consultation with the medical team. If next-of-kin or a guardian is involved, there should also be consultation with that person, and that person's informed consent or objection or denial should be obtained. Guardians do not issue DNR orders. A guardian's signature on a DNR order is simply to document the guardian's consent or assent to the order. If the guardian disagrees with a decision of the medical team not to issue a DNR order, the only recourse may be to move the ward to a different facility, which can only be done if it is determined to be in the best interest of the ward.)

Now, what if there is a complaint? Well, then a petition is brought in the probate court, and at that point, I will conduct a hearing and decide whether or not the guardian will be authorized to execute (or consent to) that DNR order. Here is how I am going to handle the cases. I don't know if all my colleagues will, but here is how I'm going to handle the cases:

I am going to first determine whether or not there is an advance directive and failing that what the individual would have wanted based on previously expressed views. The

evidentiary standard would be clear and convincing evidence to authorize the issuance of a DNR order. Now just as an aside in the *Martin* case, there was a lot about Mr. Martin saying he didn't want to live like that. But there was also some testimony that he had indicated that he didn't want life support ended; he wanted to keep going. I think that really caused the Supreme Court to have a problem with this case which is why they decided to make their own findings of fact at the Supreme Court level.

So what happens if we don't have an advance directive; we don't have any previous expressed wishes in this case? Well then I am going to go to the objective analysis, best interest. I like Dr. Tomlinson's test. It's as good a test as any.

I did have the opportunity to review the transcript of the proceedings in the Montmorency County case. In that case the Judge permitted a DNR order to withhold and withdraw life sustaining care using the *Rosebush* criteria. And he found that, using that test, the burdens of treatment substantially outweighed the expected benefits of treatment.

So, just to summarize, the guardian has the power to sign a DNR; a court order is not required; if someone objects, we'll conduct a hearing to decide what to do, and it's going to be a 3-step analysis. First, is there an advance directive; second, is there clear and convincing evidence of an express wish; and finally, failing all of that, then we are going to use the objective or best interest analysis.

Now that I know that the DNR Act doesn't apply and that the Attorney General's opinion has been overblown. Technically, the Attorney General is correct in her opinion, in so far as it went – it's just everyone has applied it to a much broader spectrum.

(A question was asked of Judge Mack about nursing care facilities that will not honor DNR orders. Judge Mack expressed some disbelief, since a DNR order is a physician order. If a nursing home refuses to honor it, the physician should document the disagreement and the bases for it in the resident's record. Judge Mack suggested the solution might be to find a different nursing home.)

I had another case where a public guardian basically wanted to have DNR orders signed for all of their wards in the nursing home regardless of their condition, including a couple of ladies who were “pleasantly demented” in no apparent distress. The nursing home declined to honor these DNR orders because they felt that it wasn’t appropriate. The guardian announced that it would be moving all the wards (about 12 or 13) out of the nursing home the next day. I was contacted by the nursing home; I prepared a temporary restraining order. We called the guardianship company and told them not to do anything. We took away their authority to move the wards without a court hearing. Just before the trial they resigned as guardians, which in theory would make the case moot. I decided I should hear the case anyway, and I decided that they did not have the authority under those circumstances to have DNR orders signed.

However, if a nursing home is saying you can’t have a DNR order signed as a matter of policy, then I think that they are just wrong. A guardian has that power under the common law (that body of Anglo-American law that has developed over the centuries).

(In response to a question, it was clarified that although a DNR order can be consented to by a guardian; it is a physician order that must be signed by at least one physician. Judge Mack also clarified that it is not lawful for a nursing care facility to refuse to honor DNR orders simply by sending a copy of the Attorney General opinion to the guardian.)

(In response to a question, Judge Mack explained that if the guardian is being inappropriate, unprofessional or otherwise irresponsible, the ward (patient) or any interested person should just put it in writing and fax it to the judge or mail it to the judge or call the judge’s assistant. He stated that in his view, Michigan is one of the most enlightened states in the process of making changes in guardianship. The judge can take action involving a fiduciary based on information received under any circumstances. You don’t have to file a petition with the court. That’s likely to trigger the appointment of a guardian ad litem, or in Wayne County, it will trigger the appointment of an

ombudsman, to come out and conduct an investigation, sometimes as quickly as within a matter of hours. Fiduciaries who are not carrying out their duties will be removed.)

If the ward makes the complaint, that will likely trigger a hearing for a new guardian. The ward would have a substantial voice in determining who should be the new guardian, unless there is clear and convincing evidence that the proposed guardian is not suitable. If a third party is involved, that will trigger at least an investigation by a guardian ad litem, or in Wayne County by an ombudsman, as to whether a new guardian should be appointed.

In 2000, the Attorney General issued an opinion which has been interpreted by many to mean a guardian cannot consent to a DNR for a developmentally disabled person. I think the opinion can be read narrower than that. The Attorney General correctly observes that a developmentally disabled person may not execute an advance directive under the Patient Advocate Act since the person must be of sound mind. The Patient Advocate Act does not authorize a guardian to act on behalf of a developmentally disabled person; therefore, the guardian has no authority to consent to a DNR under that Act. The Attorney General then looked to the Michigan Do Not Resuscitate Procedure Act for authority and concluded that a guardian may not sign a DNR under that Act. Since this Act does not apply to guardians in the first place, that's a sensible conclusion. However, all of that being said, like the Supreme Court in *Martin*, the Court of Appeals in *Rosebush*, and Montmorency County's very own Judge Mack (no relation to Judge Milton Mack), I believe guardians have the authority under the common law to execute a DNR and, therefore, the Attorney General's opinion is not an obstacle and is, in fact, irrelevant because it only refers to those two statutes. And that's my opinion and I am sticking to it.

(In response to a question it was noted that there may be an exception for a limited guardian who has only the specific authorities specified in the letters of appointment.

Otherwise, guardianship papers do not have to list the right to consent to a DNR as a specific authority.)

Dr. Tomlinson was asked about his concerns when guardians will not make decisions about limiting treatment for their ward. He responded as follows:

Dr. Tomlinson

I have made contact with the Probate Law Section because in my experience working with some hospitals, the problem is not uncommon that guardians would not make reasonable decisions about limiting treatment for their ward. The fact that it doesn't reach the Probate Court very often doesn't mean that there aren't conflicts. It just means that the conflicts don't come to the Court's attention for one reason or another. So I put together a survey.... We had almost 200 responses to that survey documenting instances or telling stories of instances where court appointed public guardians were not willing to make what to the medical staff seemed very, very sensible decisions that were really in the best interest of the patient. Since then [members of the Section] are making efforts now to propose changes to the statutes to make the powers of the guardians much more explicit so that we can give them the kind of authority they need to act in the best interest of their wards. (Some members of the panel would argue that the authority exists and that the statutes simply need to be enforced.)

Kay Felt

I am sure that many of you who have had cases that have been problematic are delighted to hear Judge Mack's cogent discussion of these cases. This presentation is being videotaped and will be available to order through Gregory Conyers' office. I think it will be very useful for many people for whom there has been all this confusion.

Mark Cody

A lawyer should never say that a judge is wrong, particularly on videotape, but you can say that you take issue with the position that the judge has adopted. And I take issue with Judge Mack's position that there is an inherent right of the guardian to consent to a DNR order because that in my judgment is a transfer of a fundamental right of the individual with the disability, the individual – the ward, if you will. To give the authority, the carte

blanche, to the guardian to make those decisions with the only check being that someone would object, it seems to me goes a step too far, and let me explain why.

Disability rights organizations such as mine, and some of the others that I listed as being part of the *Martin* case, have long been concerned about the termination of life support, particularly for individuals with disabilities, particularly for individuals with developmental disabilities who have never had the capacity and the judgment, at least the majority of individuals, to express a choice with regard to the withdrawal of life sustaining treatment.

You may be surprised if you think back to the *Schaivo* case that there were organizations – The National Organization of Protection and Advocacy Systems, the National United Cerebral Palsy Organization, the ARC and a number of other disability organizations, that joined together to file briefs in support of – in opposition, I guess really, for terminating life sustaining treatment. It was euphemistically called nutrition and hydration, which I think in most people’s minds equates to food and water. Of course, the courts ultimately allowed food and water to be withdrawn from Ms. Shaivo.

Let me try to list out quickly then some of the reasons disability rights organizations, such as mine and others, would object to or take issue with Judge Mack’s position and are very concerned about the withdrawal of life sustaining treatment, no matter who makes the decision.

First of all, inherent in that decision is too often in our judgment a quality of life assessment made by others who have never experienced developmental disability. We are quite concerned that people with developmental disability are treated as if they really lack the inherent worth of other individuals..

Too often the inability of people with developmental disabilities to communicate fully is not properly and thoroughly understood. Now I am confident that Judge Mack and many

of the other probate judges would give full credence to any efforts to try to solicit or elicit from the individual whose life is at stake what the individual's express choice would be.

Let me give you a quick example where a probate judge did give considerable time to figure out an individual's wishes. He was profoundly deaf and profoundly cognitively impaired, but did have the ability with the assistance of not only an interpreter, but also his support coordinator, to express his choice with regard to the insertion of a feeding tube which he did not want. He was able to convince the judge through these rather elaborate means of having a couple of people assisting him that he understood what a feeding tube was; he understood the consequences of not have a feeding tube; but his preference was to take his chances. And our position is that too often people with developmental disabilities are expressing choices not heard by others, sometimes not even by people in their families.

There also is the adequacy and accuracy of the medical opinion. Sometimes that's quite frankly lacking. The medical profession like all others is subject to biases and prejudices, preconceived notions about the quality of life. We have had situations in our office, where, for example, an individual with pneumonia has been denied antibiotics simply because someone is making the decisions that the individual really is on death's door.

We also had an individual who was presented to our office with a diagnosis of failure to thrive. We were able to convince the guardian not to authorize the withdrawal of life sustaining treatment. I got a call a couple of weeks after from the medical director from the community mental health organization, who reported that the client was up and doing well. The cure, believe it or not, was Burger King food. They discovered he was living in a group home where the meals were apparently sub-standard or at least not to his liking. Somebody figured out that he really always enjoyed Burger Kind food. They brought him some in the hospital; he enjoyed it and ate it. He went forward with his life, and the doctor reported back that the only thing threatening him was cardiovascular disease.

There are other concerns we have dealing specifically with the surrogate. Some people talk about the impact that this has on the family. What about the wife who sees her husband in the hospital? What about the parents who see their child in the hospital? That is not a concern that anyone should dismiss, obviously, but again, where is the focus. There is a conflation of the interest of the individual with the disability or who is requiring life sustaining treatment and the surrogate decision maker. And finally, quite frankly, there is the motivation of the surrogate decision maker that concerns us often – that someone would say, “You know what, I have been taking care of my brother with the developmental disabilities. I have been watching over him for four years, and it’s time for him to go.” We have heard words that are starkly close to those sentiments. And so, we are worried that the underlying decision of the guardian will be informed, not by a concern for the quality of life of the individual, but a concern for how it impedes the lifestyle of the surrogate decision-maker.

Let me just tack on to what Judge Mack said that if you are aware of the existence of a durable power of attorney, advance directive, that type of thing, it is important that that matter be brought to the court’s attention at the hearing before a guardian is appointed. We are actually involved in a situation in our office, not with Judge Mack, where that information was not brought to the probate court’s attention and the judge will have to sort that out. [Note: Under EPIC a guardian has no authority for medical decision-making when there is a previously-executed patient advocate designation.]

(Mr. Cody was asked whether all disabled persons should have CPR at the time of their deaths, with the question being whether that interferes with the right to die peacefully. Since CPR is normal procedure in the case of a cardiac arrest, there would need to be a DNR order not to perform it. The judge in the Montmorency County case noted testimony from one of the physicians who said, “This patient is not a science project; this person is not a windbag; how many times do we have to resuscitate her, when we know that she is not permanently resuscitatable.” Mr. Cody reflected back to the position his

agency took in the *Martin* case that there could be a DNR order if this is a terminally ill individual, and there is clear and convincing evidence that administration of CPR would cause severe unavoidable pain, then administering life sustaining treatment would be inhumane.)

[Note; In her closing statement, Kay Felt included a comment not previously made in her presentation that while it did not trouble her so much to impute to developmentally disabled who cannot communicate that 95% of the population surveyed would not want to be resuscitated if the person were severely demented, it troubled her considerably to impute to them that 50% would not want to be resuscitated in less compelling circumstances. Her conclusion is that we have to take great care that individuals, including developmentally disabled, receive as much care as they want at the end of life, and that is reasonably possible from a medical point of view.]

Dr. Tomlinson

[In response to prior speakers.] First, let me comment that actually the title of this panel and our focus on CPR, do not resuscitate, is a very, very, very, very narrow window for dealing with a tremendous range of difficult decisions at the end of life, and so we are not just talking about CPR. If that's all we are talking about; if that's all that guardians are empowered to do, then we are going to end up with some very irrational plans of care – where we are not going to resuscitate but we are going to do all these other things. And so there are all kinds of decisions that need to be made.

One of the concerns that I have about confining the prerogatives of the guardian to the circumstances in which the patient is terminally ill, is to begin with, it's not clear what you mean by that. Someone can have a diagnosis of a terminal illness, and yet, if you provide this or that or the other treatment, you might extend their life by some margin or other – it might be small – it might be relatively large, and so the question of whether someone has a terminal illness, doesn't go directly to the question of what is to be gained by the provision of this, that or the other treatment, even with regard to the extension of that person's life.

It seems to me that what's more germane is what can we accomplish with the attempt of resuscitation, or putting someone on dialysis or putting them on the ventilator or taking them to surgery or whatever it happens to be. First of all, can we in any meaningful lengths extend that individual's life. If the answer to that question is no, then it doesn't make any sense to provide that treatment, no matter what it is, even if it is antibiotics.

And then the next question is, if you can't extend it, then just what is the nature of the harms that might ensue and the benefits as well. This is where I want to be concerned about making individual judgments for everybody, including those people who are developmentally disabled. So if we have a blanket rule that wherever we can provide any kind of extension in a person's life, we are going to do it unless there are some very severe conditions that are met – they have unremitting, unrelievable pain, which hardly ever happens. Then we are going to be insensitive to the effects of treatment decisions on individuals who as individuals are going to have different needs and may suffer the effects of treatment differently because of the nature of their disability. So what I am after is how can we individuate these judgments not only for those people who have some less of expression of their preference, so we know what they wanted as individuals, but even in the case of those who are developmentally disabled, how can we individuate our decisions about what is in their best interest that permits us to make decisions that are not going to impose really unnecessary and severe burdens on them or result in considerable diminishment of the quality of life that they enjoyed before the treatment decision had to be made.

Kay Felt

I'd like to just interject something here. Let's look at the facts in the Saikewicz case, where we had a profoundly retarded man who had cancer. The treatment of choice, in an ordinary circumstance, would have been chemotherapy, and yet this would have extended his life perhaps by 2 to 12 or 14 months, and he would have had to be restrained, and he wouldn't have understood what was going on and so forth. How would you - and let's

start with Tom- how would you analyze the facts of that case in terms of the proposition that you have before you.

Dr. Tomlinson

Well I agree with their conclusion in Saikewicz. I don't want to go as far as the court did which is to sort of frame it as a kind of substituted judgment and pretend that Mr. Saikewicz would make this, that or the other decision. Rather I want to frame it in terms of are we going to have a positive effect on the quality of life that he had enjoyed for 68 years or not, and if the answer is no, then we may conclude that the treatment is not warranted because it's going to make him worse rather than keep him at his current level, or hopefully make him better. Instead, it is going to make him worse. Our obligation, when we provide medications or treatments to people, is not to make them worse. If anything, it's not to make them worse than they were before. In making that calculation things like what the experience is going to be for that patient of the treatment or the aftermath of that treatment is directly pertinent to making that decision, not in terms of what they would want, but in terms of what's in their interest. At the very least we should have a standard that says, "Let's not make them worse off than they were before."

Kay Felt

The medical testimony in the Saikewicz case was that without treatment, he would in some period of time, unclear how long, die a relatively painless death. Mark do you have anything that you want to add?

Mark Cody

No. I mean, again, my position is to always – our intent is always to push the decision of the framework or analysis closer to the subjective side of it or – I mean the objective side of it and we can't have a very narrow window of cases in which the decision to withdraw life sustaining treatment can be made on behalf of another who has never expressed a particular choice. So I am not sure. I am particularly troubled by the outcome in this case.

Kay Felt

I want to have my friend, Dr. Jean Lewandowski wave her hand. She and I were on the Governor Engler's End of Life Commission and something that happened during that I

think has some impact on what we are talking about here. And that is, that that term “terminally ill” was so difficult for physicians to deal with under the Michigan Dignified Death Act in which the physician was required to tell a patient who was theoretically terminally ill that fact and then to offer a wide range of treatment and non-treatment possibilities, including no treatment. And I always loved it that they included hospice and palliative care in the options and pain management, because as Mr. Tomlinson says, “Pain should always be dealt with.” That terminology was changed to “life limiting condition, “meaning a condition, that is more likely than not, unless something else intervenes, to cause an earlier death – more likely than not to result in the patient’s death in a relatively foreseeable period of time. It is very difficult, physicians say (I am not a physician, so I have to rely on them) to know with precision when a patient might die. As Dr. Lewandowski often said, a better question would be: “would it surprise you if your patient died” and then to trigger those questions and information to the patient on that basis. In addition to that, I think we have to look at that footnote 15 in the *Martin* case which uses the language terminally ill and begin to weigh in on that, substituting it with life limiting condition, a condition more likely to result in the patient’s ultimate death, unless some other life limiting condition intervenes. It seems to me we have to broaden our approach on those cases. (In response to as question, it was noted that one of the difficulties with the concept of terminal illness is a Medicare requirement, which is also used by some other third party payors, that for reimbursement to be allowed a physician must have determined “terminality” in terms that the physician’s medical opinion is that the patient is anticipated to die within a period of six months. That is very difficult for physicians to do.)

Kay Felt

I want to follow up with Dr. Tomlinson on a question about the *Rosebush* case, since he has questioned the court in the *Saikewicz* case for making an effort at a substituted judgment-like approach. Does the *Rosebush* case apply more broadly than to the simple question of the authority of parents to make decisions for minor children?

Dr. Tomlinson

Well I can't make much sense of that part of *Rosebush* that casts the decision as kind of a substituted judgment on behalf of Joelle Rosebush. As a decision about the proper authority of parents to make decisions on behalf of their child, in that child's best interest, I fully agree with *Rosebush* on those grounds. I guess what troubled me about it, is the way in which the basis for the decision was cast as a substituted judgment deciding for or on behalf of Joelle Rosebush, or in her name.

Mark Cody

Can I interject something here. We have heard of the frustration of the medical community with the legal community or with guardians and that type of thing. I don't think the medical community is exactly innocent in this discussion. About a year and a half ago, my mother-in-law suffered a serious heart attack and was taken to the hospital. She had previously executed the requisite durable power of attorney or advance directive giving my wife the authority to act on her behalf.

She was taken to a major medical center. My wife had all the paperwork. The nurse asked if anybody had a DPOA or was patient advocate. The nurse didn't ask to see any paperwork; there was no inquiry into whether or not my wife was in fact authorized to act on my mother-in-law's behalf. The nurse asked, "Well what does she want?" Because we had had this conversation with my mother-in-law, my wife said, "She wants the whole show; she wants to be kept alive." My mother-in-law wasn't in a position at that time or of a mind-set that she wanted anything less than every intervention that the hospital was able to provide.

With that, the nurse attempted what I thought was not a particularly subtle effort to dissuade my wife of that opinion, and to suggest that really, maybe it would just be better off if we didn't do all that "stuff" that we can do; after all she is in her 80's; she is not in great health, and so on.

Subsequently, she was admitted to the cardiac intensive care unit, where the first physician said, "This is it; call in everybody; she is not going to live the weekend." The

weekend physician and the cardiologist came in and said, “Well let’s switch up a couple of medications here and see what we’ve got,” Pretty soon she was out of the hospital and going into a nursing facility.

So, I think and I understand that medical care facilities and hospitals are under a great deal pressure, financially and otherwise, but the experience did not leave me confident that this particular facility was giving the clinical assessment that would have guided my wife in making the decisions that my mother-in-law would have wanted made.

Kay Felt

Sometimes people are confused about advance directives. That a person has an advance directive does not mean that the individual is refusing care; the advance directive is intended to specify what kind of care the person would want. I think the situation you describe is an example of that confusion. So it is very important that there be a good specific look at what does this advance directive actually say.

Dr. Tomlinson

Can I make one comment? So when someone says that they want everything done, does that mean that they want anything, even if it won’t work or what they are asking for is anything that might work or that you think will work and that’s a very critical distinction to make. And so when family or others or even in an advance directive the patient may say that I want everything done, there is a question mark around that for the people at the receiving end. Did they really mean that they want us to do anything, even if it’s not going to help or even if [it might be harmful]? Oh, well; we hope not. And so, they have to make a judgment then, about how to interpret those wishes and they also have to make decisions about what they, with regard to their own obligations, should do or not do. Because physicians and nurses also have obligations and among those is not to do harm, it’s to help people and not hurt them, and that may place limits on what they themselves, do or should do, even in response to an explicit request from a patient or family member. It is a profound ethical dilemma for physician and nurses.

Mark Cody

But, let me just tack on to that if I might. I would agree – I think one of the points of confusion arises from the fact that a lot of these documents are created in the offices of lawyers, and we don't know what we are talking about when it comes to medical issues. My mother has a very explicit advance directive. She lives in another state that spells out in great detail what's to be done under what circumstances. I can't speak with great confidence to how much she understands all of these particular ramifications. I will say that my step-father was in the hospital because he had a stroke; he had a clogged carotid artery which they wanted to clean out. The staff sat down with him in a very, very professional way and said, "We want to know what your preference is if you have a heart attack on the table; what do you want?" And he probably gave the best advance directive information that I have ever heard. He said, "Look, just let me go. I'm in my 90's and I'm not in great health, just let me go – that's fine." Then he stopped for a moment and he said, "You know, it's getting towards the end of the month. If you could keep me alive past the first of the month, my wife will get an extra pension check. So, please go ahead and do that." So, that was a well thought out and competently articulated desire. He survived and so the pension rolls on.

Kay Felt

I want to go back a little bit to this – to the questions about the *Rosebush* case and whether *Rosebush* applies more broadly than to the authority of parents to make decisions. The court in *Rosebush* was really looking at how do you define the "best interest" test in setting forth those criteria. Other commentators, such as Dr. Wier, have attempted to do something similar to define "best interest." The *Martin* court also acknowledged that Mr. Martin had been formerly competent and so "substituted judgment" was the test and specifically acknowledged the criteria that were used in *Rosebush* as applying to those people who have never been competent. I certainly don't view *Rosebush* in terms of those criteria as being limited to decisions involving children, I think that they are much broader definitionally than that. Does anybody disagree with me.

Judge Mack

I would use *Rosebush* criteria [in any case involving a person who has never been competent, and not just limited to minors]. I would use *Rosebush* criteria in any case involving a guardian who wants to issue a DNR and someone objects to it. In my view, the power of a guardian exists at common law and so I think the *Rosebush* case comes into play, unless you have someone who has a prior directive, that says keep me going at all any cost. And I suppose at that then we have, using a subjective analysis, the person has a clear desire to live no matter what, in which case you can't get to the objective standard.

Dr. Tomlinson

Sometimes, my sense is that that people think that that “substituted judgment” and “best interest” are two discrete standards. So first, you look to see if you can do a “substituted judgment.” If the answer is “no,” then you are going to “best interest.” But my view is that they are related to one another – they are like on a sliding scale along-side one another so that as the interest of the patient or the potential interest of the patient in receiving treatment or having treatment continue increases, then so does the standard; the level of evidence of that patient's wishes also increases. So the more there is at stake for the patient in receiving that treatment, the more confidence we have to have in evidence that the patient would refuse that treatment. And as the stakes for the patient go down, so for example, as the patient becomes terminal and their death is now imminent, no matter what we do, and the stakes have now gone down in receiving that treatment for the patient – so too does the level of evidence that we need regarding the patient's individual wishes regarding that treatment. We can be satisfied; we should be satisfied with a much lower level of evidence. I think, this is my interpretation, my amateur interpretation, of *Martin* that that the reason the Supreme Court wanted to have a clear and convincing evidence for Martin was precisely because in the circumstances of his condition, there was a lot at stake in the question of whether or not he was going to continue receive food and fluids because that was going to sustain a life that, at least in some perspectives, was not all that bad. And, in that case, then we need, if are going to decide not to give treatment, we need much, much better higher evidence regarding his desire to refuse it.

So, I see these as related standards not as distinct ones and which sort of how we use our – what our criteria are for “substituted judgment” is going to vary depending upon what our judgments are about the patient’s best interest.

The program ended with:

- (1) A summary by each panelist of that person’s positions as expressed in the program.
- (2) Thanks to the panelists and to all of the representatives of the State Bar who have assisted in and been supportive of the program and of opening it to the community without charge.
- (3) A reference to the State Bar website on which there will be instructions for ordering the videotape of the program.