Study L-4003 October 4, 2000

## Second Supplement to Memorandum 2000-62

## Family Consent in Health Care Decisionmaking for Adults (Additional Commentary)

We received the following comment on the realities of surrogate health care decisionmaking, and the difficulties of relying on a priority scheme, from Margaret Eaton, at the Stanford University Center for Biomedical Ethics:

I did want to send my comments to you about the proposed consensus family surrogate. I do think it creates too many problems when statutes make tight requirements in situations that differ so often. The patients and their families that we see are hardly ever the Norman Rockwell ideal that we used to think existed or on whom we could impose our White Western cultural norms. We see every combination of race, creed, nationality and economic status and what works best for us is to take the patients' families as they come to us. Sometimes we have a son but the daughter-in-law is the caregiver and is the one with a better sense of what's best for the patient. Sometimes the husband is a tyrant and bullies everyone else in the family to his will ignoring the needs of the patient. Sometimes the wife simply cannot handle the decision making and she wants a niece to speak for her after they've had their quiet conversations at home. When the family patriarch is dying, sometimes we have to hear from everyone before anyone can agree. So, sometimes the whole family wants to be involved and sometimes they want one person to speak for them or sometimes its a core of people. What seems to work best is when we take the time to assess how the particular family in question operates and attempt to obtain decisions within that structure. If we have to always impose a consensus surrogate, others in the family could feel left out and worsen the decision making process. Also, it seems to me that you need the consensus surrogate most when families cannot agree on the proper course of action. Forcing a dysfunctional family to select a consensus surrogate will almost never work since they come to us with an inability to form a consensus. We would want the flexibility to attempt resolution with an alternate structure we think will work. Once the decision is made, we can ask the family to designate the formal consent provider.

So, I would prefer that the statutes stick to stating the goal to be achieved — who is best qualified to serve the best interests of the patient — and let the hospitals and care providers figure out how this can be accomplished giving them the leeway to opt for who might be considered the less traditional but better surrogate or process. I also like the draft section that states that, where no surrogate comes forward (or where more than one person has claimed authority), the primary physician, in consultation with other health care provides or an ethics committee, may select a surrogate — but not based on a set surrogate priority but rather on a determination of who can serve best.

Respectfully submitted,

Stan Ulrich Assistant Executive Secretary