2009 SENATE HUMAN SERVICES

SB 2195

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 01/19/09

Recorder Job Number: 7221, 7234

Committee Clerk Signature Mary K Monson

Minutes:

Senator Lee opened the hearing on SB 2195.

Senator Kilzer Representing district #47. 2195 relates to the Uniform Anatomical Gift Act. The legislation was introduced at the last session and this is updating the information and procedures. Organ donation is even more important than ever. I would like you to think not only of mortality but morbidity of the problem, only the sickest are receiving organs. We would like to have more people receiving transplants.

Senator Dever Why did you replace the word organ with part?

Senator Kilzer I went to a conference to learn how to prepare the donor. There are two different types of donors 1). Person is in an accident, 2.) The other is by heart attack or something similar. When we talk about parts we are talking about organs and tissue.

Judge Gail Hagerty Uniform Law Commissioner. Spoke in support of 2195. See attachment #1.

Bruce Levi Executive Director of the ND Medical Association. Spoke in support of 2195. See attachment #2.

Senator Dever Is a driver's license for a minor sufficient to allow organ donation or can a parent over rule that?

Judge Hagerty If a person is under 18 that is the one time that people could decide not to go through with the donation after death. If someone were 17 when they got their license and died at 19, their wishes would be respected.

Senator Lee Do you know if the bar association is encouraging attorneys who work with wills and estates to discuss these things?

Bruce Levi I can't speak for the bar association but I know that there are a lot of mutual efforts; a lot of people are using the advance directive form that we put together. I am not aware of anything in particular for the bar association.

Patrick Ward Representing LifeSource. Spoke in support of 2195. See attachment #3.

Christopher T. Dodson Executive Director, ND Catholic Conference. Spoke in opposition to 2195. See attachment #4.

Senator Lee What should be done if I am an organ donor on my license and have a directive but haven't filled it out completely?

Levi I think it should be handled like any other health care procedure. It should be done according to the best interpretation of the directive. The problem here is that we're making procedures related to preparing the suitability of the organs tantamount to or above any other health care procedure.

Senator Lee Do you see any way that actions could be taken to preserve the parts or organs while the preparations are made to remove the organ?

Levi You interpret the best directive in light of everything. Ex. You need to consider religious beliefs and ethical questions.

Discussion about religious beliefs related to health directives and which takes preeminence. Ethics always follow the science. I don't know if this bill will allow my wishes to be followed.

Senator Dever Do you see a problem as it exists now or would you take a different approach to it?

Levi I don't like the existing law, but I think this will probably raise more problems. I understand that its intent is good but I would prefer if the existing law took out the word express. I think that advance directives should prevail to the extent possible.

Senator Lee Judge Hagerty, can you address Mr. Dodson's concerns?

Judge Hagerty My understanding is that with our current law, if there is a conflict, there might not be with a well written health care directive, under the current law the donor designation on the driver's license would trump. This provision is intended to raise the discussion of what the person would have wanted and to make that opportunity available to decide what their wishes would have been.

Senator Lee Is the language you are proposing in the change coming from the Uniform Laws Commission as well?

Judge Hagerty The Uniform Law was changed to include the language that is before you now in an effort to meet concerns about medical ethics from the medical community about the idea that the donor trumps even if a discussion would lead to a different conclusion.

There was no neutral testimony.

Job # 7234

Discussed waiting to act on the bill until Christopher Dodson could speak with a judge and see if there were anything he could change to make the bill more amenable to his position. There was concern that Mr. Dodson was pushing the bill to its absolute last exception. There will never be a bill that makes absolutely everyone happy.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☐ Check here for Conference Committee

Hearing Date: 01/27/2009

Recorder Job Number: 7920

Committee Clerk Signature

Minutes:

Committee discussed the opposition of Christopher Dodson. They decided they needed to make a value judgement. Most members of the committee were very comfortable with language, intent and thought that went into the bill. Senator Lee respectively disagrees with Mr. Dodson.

Senator Erbele Moved a **Do Pass** motion for SB 2195

Senator Pomeroy Seconded

Clerk called the role on the motion to **Do Pass. Yes: 6, No:0, Absent: 0.**

Senator Erbele will carry the bill.

Date: 1-27-09

Roll Call Vote #: 1

2009 SENATE STANDING COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2195

Senate Human Services Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended ☐ Rerefer to Appropriations

Motion Made By Sen. Erbele Seconded By Sen. Pomeroy

Senators	Yes	No	Senators	Yes	No
Senator Judy Lee, Chairman	✓		Senator Joan Heckaman	✓	
Senator Robert Erbele, V.Chair	✓		Senator Richard Marcellais	✓	
Senator Dick Dever	✓		Senator Jim Pomeroy	✓	

Total (Yes) 6 No 0

Absent 0

Floor Assignment Senator Erbele

If the vote is on an amendment, briefly indicate intent:

REPORT OF STANDING COMMITTEE

SB 2195: Human Services Committee (Sen. J. Lee, Chairman) recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2195 was placed on the Eleventh order on the calendar.

2009 HOUSE HUMAN SERVICES

SB 2195

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2195

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: March 17, 2099

Recorder Job Number: 11083

Committee Clerk Signature Vicky Craktree

Minutes:

Chairman Weisz opened the hearing on SB 2195.

Sen. Ralph Kilzer from District 47 sponsored and introduced the bill: This bill makes the organ donor process easier. I hope everyone has a red donor stamp on their drivers license. This bill is a fine tuning of the last bill and makes it more feasible and easier. Ask for your consideration.

Chairman Weisz: We no longer call them organs, they say they are parts?

Sen. Kilzer: A better definition is to talk about tissues or organs. There are seven major organs available from a human body, two kidneys, two lungs, heart, pancreas, not sure what the other one is. Then there is also tissues like eye tissues. Parts kind of covers everything.

Rep. Damschen: Page 2, line 10 the last word, don't know how to pronounce it.

Sen. Kilzer: Contraindicator? In medicine we have a lot of indications for doing something. For example if you have high blood pressure it could well be an indication that you should be taking this medicine. A contraindication is the opposite. If you have this then you should not do this.

Patrick Ward representing Life Source: See Testimony #1.

Bruce Levi, Executive Director ND Medical Association: See Testimony #2.

Chairman Weisz: The last section where it talks about not contraindicated. If something was expressly stated in the directive as would be under current law, that part now seems to trump that statement. In other words, to me most of it is (inaudible) approval, but then when you get to that last statement and because it is a conflict and so now your again specifically trumping the healthcare directive (inaudible) to you.

Bruce Levi: I think it is less of a trump. What you are doing is recognizing the current practice ruling involving if we have conflict we go to the agent and resolve that issue. The idea is that individual is going to have a perspective donor of the patient is going to have (inaudible) conversations with their agent and that person is in the best position to make decisions about that individual's values and what they would want at the end of life. They provide some direction on their donor card and hopefully they have talked to their agent and that person can assist in making that decision. The bill language is less specific in not stating specifically that one trumps the other. I think it leaves it open to some flexibility so the physician can work with the agent and work with whoever else is involved.

Chairman Weisz: I agree until you get to lines 10 and 11 on page 2 and then I think we are shifting back to other direction again.

Rep. Frantsvog: One of your opening comments was that as the law is now organ donations comes from your best directive. I'm assuming that this legislation tries to reverse that, but probably doesn't in total. Instead leaves some room for negotiation, is that correct?

Bruce Levi: Not negotiation, but resolution of the conflict to determine the intent of the individual is, but your right, I don't think the pendulum shifts all the way back to the other side.

OPPOSITION:

Chris Dobson, Executive Director Catholic Conference: See Testimony #3

Rep. Conrad: Can you give me an example of where it would not be consistent with the (inaudible).

Chris Dobson: I have it listed, but it is all medical stuff. There was disagreements among physicians and presenters at the workshop we held on how much heparin to give someone who is going to be an organ donor. You have ethical principles and what happens in the act and not just what the outcome is in the act. There was also anticoagulants and other things I was told that they disagreed on. Bottom line there are questions involved here that should be decided according to a person's wishes.

Rep. Conrad: How would the physician know what the religious wishes would be?

Chris Dobson: We never expect an agent or physician to know. That is why we encourage people to appoint an agent and then the agent does the best they can on their knowledge.

Chairman Weisz closed the hearing.

2009 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. 2195

House Human Services Committee

☐ Check here for Conference Committee

Hearing Date: March 18, 2009

Recorder Job Number: 11201

Committee Clerk Signature Vicky Crabtree

Minutes:

Chairman Weisz: 2195 that's the uniform (drops sentence). I'll hand these amendments out. For those of you who were around you are well aware I didn't think much of this bill last session. I had a real problem with reading 15 pages to tell someone you can donate an organ. I'm all for organ donation, but I don't know why we have to make it as complicated as it did last session. This amendment is from the Catholic Conference. I don't believe Life Source will like these amendments. They haven't seen them yet. They will want the organ donation to have priority. I kind of like the amendment suggestion.

Rep. Pietsch: I think Senator Kilzer mentioned that the directive should be first.

(Everyone talking at once.)

Chairman Weisz: The conflict has to be resolved by the wishes of the health care giver. That's why Life Source doesn't like this language because they want that part to be dying while they are arguing over the health care directive.

Rep. Holman: I like this over the previous one. I see real conflict in the previous one because you have to people on equal footing probably figure out a way to coerced their way over what might have been the deceased wishes.

Chairman Weisz: I did get an amendment from Life Source, but all it really did was still specify that the organ donation took priority, but it tried to speed up the conflict solution a bit. So while that was still going on it still meant you couldn't do anything to prohibit the organ donation.

Rep. Nathe: I work with Life Source everyday and they can be very aggressive at time. I had a family in my office and they even approached us to talk to family when they are making pre-arrangements and I resisted that as I feel that should be done outside of my business.

Rep. Damschen: Motion to accept the amendment.

Rep. Nathe: Second.

Voice Vote: 12 yes, 1 no, 0 absent.

Rep. Porter: Do Pass as amended.

Rep. Kilichowski.

Rep. Damschen: I have a friend who was on life support and they disconnected the life support and he got better and is walking around today. I'm curious as to when do they harvest the organs from the donor. If they are on life support and they family says pull the plug.

Chairman Weisz: They don't try to do anything to damage the organ and they don't harvest it prior to official death, but they do procedures after death to preserve them.

Rep. Porter: There are different levels of death. And the organ donor business is brain dead. They do the EEGs and tests to determine brain death. Once it has been determined. The transplanting team actually causes the biological death of the body. As long as you have electrical activity of the brain you are not at the level of organ donation. The connective tissue of the eyes taken after full biological death. The heart, lungs and liver they can't.

Chairman Weisz: How long do they have on those?

Rep. Porter: Sometimes the systemic organs shut down prior to brain death so then they take certain organs like kidneys. Prime donors are massive strokes and head injuries and attempted suicide.

Roll Call Vote: 12 yes, 1 no, 0 absent.

MOTION CARRIED DO PASS.

BILL CARRIER: Rep. Conklin.

Adopted by the Human Services Committee
March 18, 2009

VR
3/18/0

PROPOSED AMENDMENTS TO SENATE BILL NO. 2195

Page 2, replace lines 1 through 11 with "the attending physician, as expeditiously as possible, shall confer with an agent acting under the prospective donor's declaration or directive or, if none or the agent is not reasonably available, another person authorized by law other than this chapter to make health care decisions on behalf of the prospective donor. In resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs, as stated orally, or as contained in the declaration or advance health care directive."

Renumber accordingly

Date: 3-18-09

Roll Call Vote #: 1

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2195

House HUMAN SERVICES Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken ☒ Do Pass ☐ Do Not Pass ☐ Amended

Motion Made By Rep Damschen Seconded By Rep. Nathe

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN ROBIN WEISZ			REP. TOM CONKLIN		
VICE-CHAIR VONNIE PIETSCH			REP. KARI L CONRAD		
REP. CHUCK DAMSCHEN			REP. RICHARD HOLMAN		
REP. ROBERT FRANTSVOG			REP. ROBERT KILICHOWSKI		
REP. CURT HOFSTAD			REP. LOUISE POTTER		
REP. MICHAEL R. NATHE					
REP. TODD PORTER					
REP. GERRY UGLEM					

Total (Yes) 12 No 1

Absent _____

Bill Carrier _____

If the vote is on an amendment, briefly indicate intent:

Motion Passed

motion to accept Amend.

Date: 3-18-09
Roll Call Vote #: 2

2009 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. 2195

House HUMAN SERVICES Committee

☐ Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken ☒ Do Pass ☐ Do Not Pass ☒ Amended

Motion Made By Rep PORTER Seconded By Rep Kilichowski

Representatives	Yes	No	Representatives	Yes	No
CHAIRMAN ROBIN WEISZ	✓		REP. TOM CONKLIN	✓	
VICE-CHAIR VONNIE PIETSCH	✓		REP. KARI L CONRAD	✓	
REP. CHUCK DAMSCHEN	✓		REP. RICHARD HOLMAN	✓	
REP. ROBERT FRANTSVOG		✓	REP. ROBERT KILICHOWSKI	✓	
REP. CURT HOFSTAD	✓		REP. LOUISE POTTER	✓	
REP. MICHAEL R. NATHE	✓				
REP. TODD PORTER	✓				
REP. GERRY UGLEM	✓				

Total (Yes) 12 No 1

Absent 0

Bill Carrier Rep. Conklin

If the vote is on an amendment, briefly indicate intent:

Motion carried
D Pass
amended

REPORT OF STANDING COMMITTEE

SB 2195: Human Services Committee (Rep. Weisz, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (12 YEAS, 1 NAY, 0 ABSENT AND NOT VOTING). SB 2195 was placed on the Sixth order on the calendar.

Page 2, replace lines 1 through 11 with "the attending physician, as expeditiously as possible, shall confer with an agent acting under the prospective donor's declaration or directive or, if none or the agent is not reasonably available, another person authorized by law other than this chapter to make health care decisions on behalf of the prospective donor. In resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs, as stated orally, or as contained in the declaration or advance health care directive."

Renumber accordingly

2009 SENATE HUMAN SERVICES

CONFERENCE COMMITTEE

SB 2195

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☒ Check here for Conference Committee

Hearing Date: 4-15-09

Recorder Job Number: 11881

Committee Clerk Signature Mary K Monson

Minutes:

Senator Erbele opened the conference committee on SB 2195. All members were present: Senator Erbele, Senator J. Lee, Senator Marcellais, Rep. Porter, Rep. Weisz, and Rep. Kilichowski.

Rep. Porter explained that the House amendments came about because there were those who felt that organs were being put above life. Other states said they would not adopt this act because the organs have more authority than the person's life. The House wanted to make it very clear that they did not – that there was a very solid line drawn between the difference between the rights of the organ donation and the rights of the patient.

Rep. Weisz said although they are all supportive of organ donation they want to make sure the end of life directives took priority and the organ donation would have to fit within that scope. The House felt the law tended to give the organ donation precedence.

(Meter 04:10) Some examples were given by **Senator J. Lee** to try to understand procedures when not trying to extend life beyond a reasonable time but just to procure the organs. Discussion followed that the advance directives is a document that a person needs to take time to understand and sign whereas to be a donor takes only a short time at the DOT without

fully understanding the organ procurement process. Part of the thought process is that inside of the health care directive the potential conflicts of organ donation should be addressed.

The advance directive could be more specific to address the "what if" situation.

Should state law trump the wishes of a directive with the organ donor question? The House didn't think it should.

The legislature dealt with the advanced health care twice in the past. It was made into one document in 05.

Rep. Weisz said that part of the problem might be that they didn't look at organ donation as it fit within the bigger picture.

People look at organ donation as being done after they are gone but the advance health care directive is when a person is still alive. There is a gray area here.

Senator Erbele opened up the discussion to include comments from others in the room.

Christopher Dodson, ND Catholic Conference, offered information to further the discussion. He said they weren't really talking about whether it was a conflict of whether the person wants to be a donor and their health care directive indicates that. It's determining whether a particular act related to the donation procurement is consistent with what the patient's wishes are. Examples – sustain life through ventilation or providing measures like high doses of heparin and anticoagulants (meter 15:10). There are procedures that are involved in maintaining the suitability of organs that do raise ethical questions for some people. That's where they feel the directives should determine whether that procedure is appropriate.

The Conference prefers the House position.

Two proposed amendments were presented to the committee – attachment #1 from Lifesource (Patrick Ward) and attachment #2 from Christopher Dodson. Mr. Dodson agreed with everything on the Lifesource amendment except on page 2, line 8 he wanted "life prolonging"

before measures. He explained their position was that the advance directive shall prevail but if there is going to be a compromise a distinction needs to be made between those measures which have a secondary effect of prolonging life and don't harm the patient and those measures which do not burden the patient or are abusive to the patient but still may be a problem. Life prolonging was the best he could come up with for things such as a ventilator or things where life is being sustained for a temporary time to maintain the suitability of organs while this process is taken care of as opposed to allowing procedures that may harm the patient in the dying process or serve no benefit to the patient.

Rep. Porter pointed out that in the end the goal would be to have the individual make it clear inside their advance directive how they want this to happen. Then this wouldn't trump that advance directive.

Patrick Ward, Lifesource – the organ procurement association for the upper Midwest, said the one issue that is a sticking point for his clients is the use of the term "life prolonging". It depends on how life is defined, whether prolonging life or sustaining life, or sustaining the organ temporarily, while making the decision. This particular statute is really an issue of the organ donation trumping the directive or vice versa and only a situation where it is unclear what the person wanted. He suggested those helping people write wills and health care directives are usually going to be attorneys and this is something they should be talking to people about. He pointed out that people have signed something saying they wouldn't want their life unnecessarily prolonged. At the same time they signed something else saying they want to be an organ donor. When they are on their deathbed someone has to make the decision as to what that person really wanted. He thought this bill addresses the time period where that decision is being made. The use of "life sustaining" was not as quite as bothersome to him or his clients as "life prolonging". What they are trying to address is the

situation where the person clearly wanted to be a donor but clearly didn't want their life unnecessarily prolonged.

Senator Erbele asked about just using the word "sustaining" and not using the word "life" at all.

Mr. Ward said they probably would prefer that but he also felt that's what the language in there now was really saying - that you are sustaining whatever particular organ you are trying to salvage. The real problem is that it's a situation that most people haven't thought about when they signed the health care directive, especially those older ones where it wasn't spelled out as clearly as it is today. Most people don't realize that you may need to be kept on a ventilator a little longer in order for the organs to be usable.

Rep. Weisz looking at the language passed out of the House - it says the agent will make that call. In most cases there is somebody involved in that decision and that is what the House looked at. He asked why, from Lifesource perspective, they would have an issue with saying the agent authorized by that patient calls the shots.

Mr. Ward didn't think they had a problem with that. That is what they are saying and he expanded on that answer with examples (meter 29:45). He felt what they were addressing is the time period when the decision is in the process of being made.

Senator J. Lee, addressing Mr. Ward, said it was her understanding that what they had worked on includes everything the House put in. Nothing had been removed. Their proposal was acceding to the House amendments with having some additions. (Meter 33:00) Part of the window of time they are talking about is that the survivors need time to accept the situation. Another aspect is that some organs can be harvested in most local hospitals but others may need somebody from a specialty facility and it takes them a little time to get there.

There are many different kinds of situations with different personalities and emotions involved at this time as well as legal documents.

She suggested the advance directives that are being drafted include more clear data about what people wish to do in these circumstances.

Mr. Ward agreed and said what they are trying to do is allow time to sort out if that was the intention of the dying person.

Rep. Porter saw the differences with putting something before the word "measures" as going to the next step of the high dose heparin or other medical treatments specifically aimed at the procurement of the organ rather than the procurement of life. He asked again why the organ would trump life when it comes down to this level.

Mr. Ward didn't think they were saying the organ would trump the life but the individual's intention (meter 38:45).

Mr. Dodson – under any scenario under our law it still is not acceptable to start the organ procurement until the person is legally dead - a medical determination with the parameters set by law. When talking about life sustaining they are talking about those measures which would prolong or sustain until that time comes when there is actual brain death or complete cessation of cardiac function. There is disagreement as to whether such as high doses of heparin have any benefit to the person and whether they actually enhance the dying process or can be burdensome to the patient when they serve no purpose other than maintaining the organ.

It's important to distinguish between those measures which are good and have an unintended or notable double effect such as pain medication in the dying process (meter 41:20).

He would suggest that when most people do their organ donation card they haven't thought ahead that the decisions regarding that are going to be treated any differently than any other health care decision.

The House language actually mirrors the language that is used in health care decisions elsewhere in the code.

(Meter 44:15) There was discussion that once the person is legally dead the directive doesn't apply. If the patient is declared brain dead there is no conflict anymore.

Mr. Dodson said that there are two definitions of dead and typically the definition that is used in an organ donation situation is the cessation of cardiac function.

Rep. Porter – then how would a heart and lung organ donor team be able to harvest. The heart still has to be beating?

Mr. Dodson said that is why they developed the brain dead definition.

Discussion continued on whether the conflict is resolved once the brain is dead under the definition of death.

The definition of dead was read from the code: An individual who has sustained either irreversible cessation of circulatory and respiratory functions or irreversible cessation of all functions of the entire brain including the brain stem is dead.

Rep. Porter said that for the purpose of organ procurement the cardiac function doesn't apply because nothing is viable.

Senator J. Lee asked if there was some consensus among the committee members on the proposed amendments with the exception of talking about the life prolonging and life sustaining part of it.

Rep. Weisz wanted to know what it means – "any other person authorized to make a gift".

Mr. Dodson said the language is in the original bill. He thought it was unnecessary.

There was discussion and consensus that the first section was ok. They were down to the section whether they want to have life prolonging, life sustaining, sustaining, or nothing.

When is the end date of the document? If the experts are unclear, then maybe they need to make it clear. That might take care of a lot of the potential conflicts that exist inside of the anatomical gift act.

Senator Erbele asked what the current practice is when the heat is on and the situation is there.

Bruce Levi, Medical Association, replied that this situation doesn't come up very often. From their perspective they try to incorporate the uniform anatomical gift piece into the advance directive. He was not aware of any specific provision that cuts off the applicability of the advance directive upon death. In most cases they will be deferring to the agent when talking about what the wishes of the donor are.

Rep. Weisz felt it was important to know if the health care directive disappears upon death or if it still applies after the legal definition of death.

Senator J. Lee – if the advance directive expires at death, the donor designation does not. Then there is no issue.

The conference committee adjourned for the day.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☒ Check here for Conference Committee

Hearing Date: 4-20-09

Recorder Job Number: 11977

Committee Clerk Signature Mary K Monson

Minutes:

Senator Erbele called the conference committee to order to continue discussions on SB 2195.

All members were present.

Attachment #3– letter from Mr. Ward

Attachment #4– letter from Lifesource

He reminded the committee that there had been agreement with the group of using the word "sustaining" as long as they don't speak to life. They are just talking about keeping the organ viable for donation.

Rep. Porter interpreted that after one of the two events has taken place, either brain dead or cardiac death, the directive would no longer be valid. The original language the House sent over would then be, in his mind, the most fitting (meter 02:40).

He wanted to make sure that the directive document is done at the point of one of those two events taking place. Then all of the other arguments fall into place. The document protects them up to that event then it is the donor card. It makes it clear that the document is still putting the individual above the organ up to that event.

Senator J. Lee pointed out that the organ donation would never be done without the families' involvement. She wanted to know if Mr. Ward and Mr. Levi agreed that the House version is what needs to be or if there is still concern.

Senator Erbele felt the proposed amendment was easier to read. The House version didn't specifically say brain dead or cardiac dead.

Senator J. Lee asked if the bill as it came from the House was appropriate now that they had the additional information or is the amendment from Mr. Ward necessary in order to accomplish what the committee agreed they needed to do.

Senator Erbele asked Mr. Ward and/or Mr. Levi to speak to the question.

Mr. Ward, Lifesource, said they would like to see the additional sentences inserted. They would like to see the sentence "Information relevant to the resolution....." (from attachment #1) inserted into the House amendment. They think the second part clarifies the authority to keep the part alive while the person who needs to make the decision is found.

This language inserted into the House amendment just makes clear what happens in those minutes or hours in between the time the person is legally dead or on the imminent brink of legal death and it is time to make a decision to somehow preserve an organ for transplantation.

Bruce Levi, Medical Association, agreed. The clarification of the measures to sustain the suitability of the part is important. He felt if it was left as it is there is an ambiguity in terms of where they are at in the conflict and what happens while the conflict is being resolved.

Rep. Weisz thought they needed to define where the conflict occurred because the conflict can only occur after death. If it is prior to death, it is the perspective of the House that the health care directive takes precedence. To him it seemed that when they talked resolution and

conflict they were meaning that minutes and hours after legal death before harvesting the organs.

Mr. Ward – technically there would be no conflict after death in that the health care directive is done but there might be a misunderstanding out there among the family or with the physician or someone involved in the process (meter 09:40).

Rep. Weisz felt it makes it more confusing and they would have to define if this conflict occurred after legal death. If they are living, by definition the health care directive is in place and that is what has to be followed. But any conflict that arises has to arrive after death in that gray area.

Mr. Ward said there might be some scenarios where the conflict is prior to death (meter 11:00).

Senator J. Lee – didn't think there was a conflict. There is a stopping of one thing and the starting of another.

Rep. Weisz said that was his point. Why the language pg. 2 line 8 when there isn't a conflict. (Meter 14:00) There was discussion that maybe the solution would be to eliminate the phrase "before resolution of the conflict". The use of the word sustaining was ok. There will be instances where the individual is still legally alive and the issue comes up whether or not the health care directive is consistent with the donor designation. If the health care directive is clear then there is no conflict. The only time this comes into play is when there is confusion as to what the individual intends.

Mr. Ward thought where they were disagreeing was in a situation where the individual hasn't made it clear to allow the physician to take measures to keep the organ or part alive long enough to make sure that someone who knows the intention can provide guidance.

Senator J. Lee pointed out that the agent occasionally might say, no, they didn't want the donation to take place.

Rep. Porter didn't necessarily agree with that. It may be the case when the person is still alive but once they are declared legally dead the agent has no say in whether the donation occurs or not. The donation would occur after the point of being legally dead because an agent does not have the authority to withdraw the donor status of an individual upon legal death.

Mr. Ward said that wasn't true. The agent's authority in the UAG Act, for the purposes of donation, does survive with the issue of organ donation. It doesn't in the health care directive statute.

Rep. Porter – Who assigns that agent?

Mr. Ward – It's generally the agent that has been selected by the individual.

More discussion took place on the conflict and what would happen in such a case.

Senator Erbele adjourned the conference committee.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☒ Check here for Conference Committee

Hearing Date: 4-22-09

Recorder Job Number: 12107

Committee Clerk Signature Mary K Monson

Minutes:

Chairman Erbele Opened the hearing on SB 2195. Spoke with several different parties about the bill. The caution that was raised regarded "uniformity." Some similar bills have come up in other states and been killed, they would rather see the bill killed than add steps. The suggestion has been that in the house amendments we eliminate the first half of the paragraph because it is already stated in the bill, that was most onerous part of the language that would affect the uniformity (on the .0101 amendment)—handed out a proposed amendment .0102. (Attachment #9) The last sentence would be very acceptable to put in at the end. Discussion and review of the amendment which brings the bill back to the .0100 version and inserts the house language into the middle of line 5

Senator J. Lee As I recall one of the lawyers that visited with us last time told us also that this was redundant language.

Representative Porter I guess with the sides sitting here, I would be interested in hearing from Mr. Levi and Mr. Dodson in regards to their views on the amendment.

Bruce Levi NDMA. We supported the bill as originally introduced. In the context of the uniform law commissioners we feel this addresses the issue in terms of how the agent's decision making progress would be followed and be consistent with our current language in our

advanced directive. From our perspective, I don't see a problem with this approach of maintaining the original bill and putting in this language. I think this an area where we are grappling with an issue that doesn't arise very often. I think a lot of physicians seem to be comfortable with setting up a process as long as they know what it is, that this is an appropriate approach.

Chairman Erbele That is my personal feeling as well. I think in real life the issues are worked out. I have personally been a part of life sustaining measures such as ventilation in order to save the organs. You work these things out in real life.

Christopher Dodson, ND Catholic Conference. I think you need to keep in mind there are 2 purposes for the bill. One is to set up the parameters or standards for how conflicts are resolved—I think this amendment does that and I have no problem with that. The second purpose of the bill is to determine what measures can be taken pending the resolution of the conflict. As I understand it, this amendment would leave in the part that pending resolution they can take measures to ensure the suitability of the part. That last sentence of the bill will still be there and that part is problematic. It is problematic because it says physically that people can take measures to ensure the suitability of the part without any permission from anyone. Otherwise, it's not necessary. If you took that part out of the bill, there is nothing preventing an organ procurement team from taking measures to ensure the suitability of the part pending resolution of the conflict.

Chairman Erbele Doesn't that speak to it there on that last line?

Dodson But there is nothing there now preventing them from taking those measures so long as they have permission from the agent or surrogate to do that because we know by definition of this bill that the advance directive doesn't prohibit it. The only purpose for having that language in the law is to give permission to go ahead and without permission from the

surrogate or the agent, that is permission from no one. That is what is problematic. When we come to these sorts of decisions there are two philosophical views, do no harm view—which is what my conference often represents, the personal autonomy view, and the utilitarian view which says to heck with the personal autonomy view so long as we get a good outcome. That is what my concern is about with this last line of the bill. It trumps the view of the patient, it trumps the do no harm perspective and says that so long as it has a good it allowed. We do not do that with any other procedure in health care. Again, I don't think we need to have it there.

Senator Lee So does that mean then that you would be more comfortable if that last sentence were removed?

Dodson If that last line was removed and these amendments were added, I think we would be fine but again I am not seeing the whole bill.

Senator Lee I think philosophically we might not be seeing this the same way, I respect your position; I just don't think I totally agree with it. I don't have a problem with the fact that a physician knowing that an agent has to be reached and it is all happening before an agent can get there that they would maintain that body in a state of suspension so the decision could then be made about donation because the decision is then made for the agent if they do not keep the organs viable. I don't have a problem with that. Spoke about donation under an advanced directive. I don't see a problem here, it is not that I think the donor aspect should always come out on top but the decision is made for the family if they can't even be allowed the time it takes to get to the place where they can make the decision. I don't think that is right either.

Chairman Erbele I would ask if this is an intellectual/philosophical question or is there something in real life that has happened that is causing this concern?

Dodson First in real life, we do know that there are ethical concerns with maintaining the suitability of a part. I guess I would reverse the question though and ask do we know that there are situations where we haven't been able to maintain suitability of an organ while we future out the conflict. We haven't had any evidence of that presented. No testimony like that was presented in any other states as well. I think we need to remember that we are talking about a case where we have an advanced directive and we have an agent involved, we are talking about a limited amount of time and we know there is a conflict and there is an organ donation list, it's just a matter of resolving the conflict. Other than emergency care, we don't allow procedures without informed consent. Spoke at length about decision making processes

Representative Weisz I am thinking about the case of an 18 year old without an advanced directive that was presented and none of this would apply to that situation anyway.

Senator Lee I know I had a bad example and I apologize.

Representative Weisz If you do have someone and they do have an advanced care director and I have to assume that if there is a question that the medical person is not going to pull the plug until the agent arrives. Again it doesn't seem that the suitability of the part is jeopardized so know you have the agent involved—to me.....

Kara Johnson, Lifesource. The assertion of this amendment back into the original seems like it would be fine. My only concern would perhaps be the phrase "stated orally." Just since that will raise other issues of documentation of how we know the wishes of the donor. As far as Mr. Dodson's concerns about trumping the owner's wishes that is why there is this conflict because we want to make sure that they are following with the intent of the donor through the designation of the donor status. By removing that last line the bill effectively does nothing. But that is one of the main concerns which is why we grappled with the language. The intent is to

figure out what controls when, by removing that statement we have provided no clarification for the medical community.

Senator Lee What is the downside of just having this bill go away?

Johnson At this point, not much. Obviously you guys spent a lot of time and effort trying to make this work but as it stands at this moment it doesn't seem like you can agree.

Senator Lee My concern is that we do not mess with the uniformity and we kind of lost that thought until we started visiting with Jennifer Clark in legislative council. It is no longer uniform if we mess it up. Today, even if we pass this in some form it won't go into effect for awhile. Today if the situation were to come up, how would it be addressed?

Johnson Practically from a medical standpoint, I am going to have to defer to Mr. Levi. As far as we believe, there will be disputes and potentially court action against the physician for the action that we took. It might be clearer as to whether or not there has been a violation.

Representative Weisz Can you list us situations where this situation has occurred?

Johnson I would have to do some research into that, I am not sure off of the top of my head.

Representative Porter It seems that with the proposed .0102 amendment that it actually moved the parties further apart than with the amendment proposed by Mr. Ward on 04/15/09 where the parties were 95% in agreement other than in one area. Now we have actually moved apart from the groups. As far as the uniformity of the law, as this was being presented around the country last session, other states picked up on the flaw in the uniform law and didn't pass it because of these conflicts. As far as uniformity is concerned, this law really has a long way to go before it becomes a truly uniform law because it has not been adopted by very many states as of yet. It appears on the surface that the previous version from Mr. Ward was a bit more acceptable to the presenting parties. As far as the bill just going away for another

18months, if there were to be a conflict it is going to be a pretty ugly one if we don't address the conflict portion.

Chairman Erbele I respectfully disagree.

Dodson We would be fine with this amendment and the elimination of that last sentence. That is where the problem is. Just a reminder, if you defeat the bill, it is not uniform with anybody as this bill was proposed to fix the uniform law.

Senator Lee I know that the stake holders here spent a lot of time talking to each other and it is really hard to come up with an answer but I am wondering if they would be willing to look at what has been prepared by legislative council as well as the comments of Judge Hagerty because I think everyone wants to fix this so it is workable but we are not the legal people.

Chairman Erbele Adjourned the committee.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☒ Check here for Conference Committee

Hearing Date: 04/23/2009

Recorder Job Number: 12142

Committee Clerk Signature Mary K Monson

Minutes:

Chairman Erbele Reopened the conference committee on SB 2195.

Representative Weisz Passed out some amendments. See attachment #5. I am willing to support this, maybe there are still some problems on the other side. From what I see, I don't think this should be a problem for us.

Senator Lee I did ask for the number of states that have passed UAGA and there are 36. Passed out the map of states, see attachment #6. I also spoke with Judge Hagerty. He said that this has been a priority for him at the uniform laws commission. They see this as something that is extremely important. Similar legislation has been introduced in 9 states.

Christopher Dodson, ND Catholic Conference. See attachment #7 UAGA guidelines. What happened is that the Maryland Catholic Conference had worked with the organ procurement organization and the uniform laws commission and they came up with a set of agreements as amendments to the act which I felt were relevant to our discussion. I called Judge Haggerty and he said that these changes would be consistent with the intent of the act. In Maryland this bill is being introduced and it is being touted as a model for any states that have not yet introduced it. Explained his amendment, this is a workable compromise for him.

Chairman Erbele It seems to me as a layperson that the term "living" opens it up more.

Representative Weisz I am still not thrilled with this language but I think it is clear that it allows them to do the medical suitability piece by allowing them to be put on a ventilator until the conflict can be resolved. I sure hope that we would never do anything that is harmful to the individual who is still not legally dead to harvest the organ. I understand the compromise here, I really think it addresses some of the issues we have been concerned with.

Dodson There is disagreement as to whether high doses of Heparin and vasodilators are harmful to a patient. There is disagreement about their role in end of life care and as long as that debate is out there we need to establish parameters if we are going to give permission.

Karen Johnson Lifesource. See attachment #8. We will agree with pg 2 line 4&5, those amendments were ok. I have an amendment that just includes those lines. We are not comfortable with adding a new section to this bill which we haven't discussed. We need to take a little bit of time to examine what the ramifications are. We also like the language (inaudible), we think it allows more clarity to the medical profession. As far as end of life care that might be harmful, there are no studies that show that Heparin causes death; high doses are only given in extreme cases. Normally vasodilators are only used after there has been death and they are also not seen as harmful outside of cases involving hypertension. We are uncomfortable with the Maryland language as that language is not used anywhere else in ND, we don't want to create new language that is undefined.

Bruce Levi NDMA. I would like to provide additional comments as well. I look at it and see that we are focusing on the conflict as a conflict between the person who is providing the organ donation vs. the conflict over whether we are going to sustain the organ until the conflict can be resolved. I think the amendment is a step in the right direction as it is focusing on the conflict we are trying to resolve. I agree with Representative Weisz that it takes us in that

direction. I am not aware if this is a formal UAGA position. I remember my own legislative council had uniform laws and the need to keep things uniform. Talked about the need for uniform laws and the books available on it at the Supreme Court library. I am also comfortable with the language contra indicated by appropriate care but that is more of an objective medical standard than harmful. Who decides what is harmful? Obviously there is a debate, but the language indicated by contra as appropriate end of life care was a phrase we never fully discussed. To me harmful is more objective than what contra indicated. The other comment I had was that adding new section 1 goes beyond the scope of the bill and addressing the intent of the patient. This goes into all realms of organ procurement and I just wanted to point out that I think it goes beyond the issue we have here. Beyond that though, I think this has taken us to a place that allows us to address the conflict and proper language. There is a typo in the revision on section 1, subsection 3.

Chairman Erbele What do you think of Ms. Johnson's amendments?

Levi We have no problem with the amendment. Extrapolated on his view

Senator J. Lee I think we are all really anxious to make this work but we may need to meet another time. I'm thinking it would be helpful due to the brevity of time available to find out how this fits in with the UAGA. Perhaps the contra phrase would be a little more acceptable. I just can't imagine that anyone in the medical community would do anything harmful. It seems the contra indicated is more helpful. It also seems to me that we are trying to do this so tightly that it covers every possible situation and I don't know if that is realistic. The common sense says that everyone involved with this is going to be sensitive to the needs of the family.

Chairman Erbele We can't micromanage professional ethics.

Senator J. Lee I prefer to think that the people who are performing the medical services are obligated to behave in the same way. I think we need time to figure out if there is any additional concern about that last paragraph.

Chairman Erbele We are adjourned.

2009 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2195

Senate Human Services Committee

☒ Check here for Conference Committee

Hearing Date: 4-24-09

Recorder Job Number: 12214

Committee Clerk Signature	Mary K Monson

Minutes:

Senator Erbele opened the conference committee on SB 2195. Attendance was taken with the following members present: Senator Erbele, Senator J. Lee, Senator Marcellais, Rep. Porter, and Rep. Kilichowski. Absent: Rep. Weisz.

Amendment .0104, dated April-24-09, was distributed and reviewed. The amendment goes back to version .0100.

Rep. Porter suggested having the three interested parties give their take on the amendments.

Senator Erbele invited each of them to give their position.

Chris Dodson, ND Catholic Conference, the new section 1 makes it consistent with the language in subsection 20 of the act. He said they could live with the amendment.

Karen Johnson, Lifesource, said they agreed with the amendments. They felt it was a fair compromise.

Bruce Levi, ND Medical Association, also agreed with the amendments.

Rep. Porter made a motion for the **House to recede from their amendments and amend as follows.** Second by **Rep. Kilichowski**.

Roll call vote 5-0-1. Motion carried.

Date: 4-15-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB2195 as (re) engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
- ☐ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ pages(s) _____--_____

- ☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) _____ was placed on the Seventh order of business on the calendar.

Motion Made By _____ Seconded By _____

Senators	4/15/09			Yes	No		Representatives	4/15/09			Yes	No
Senator Erbele	P						**Rep. Porter**	P				
Senator J. Lee	P						**Rep. Weisz**	P				
Senator Marcellais	P						**Rep. Kilichowski**	P				

Vote Count _____ Yes _____ No _____ Absent

Senate Carrier _____ **House Carrier** _____

LC NO._____._____ of amendment

LC NO._____._____ of engrossment

Emergency clause added or deleted _____

Statement of purpose of amendment _____

Date: 4-20-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB2195 as (re) engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
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Senate/House Amendments on SJ/HJ pages(s) _____--_____

☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) _____ was placed on the Seventh order of business on the calendar.

Motion Made By _____ Seconded By _____

Senators				Yes	No		Representatives				Yes	No
Senator Erbele	P						**Rep. Porter**	P				
Senator J. Lee	P						**Rep. Weisz**	P				
Senator Marcellais	P						**Rep. Kilichowski**	P				

Vote Count _____ Yes _____ No _____ Absent

Senate Carrier _____ **House Carrier** _____

LC NO._____._____ of amendment

LC NO._____._____ of engrossment

Emergency clause added or deleted_____

Statement of purpose of amendment_____

Date: 4-22-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2195 as (re) engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
- ☐ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ pages(s) _____--_____

☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) _____ was placed on the Seventh order of business on the calendar.

Motion Made By _____ Seconded By _____

Senators				Yes	No		Representatives				Yes	No
Senator Erbele	P						**Rep. Porter**	P				
Senator J. Lee	P						**Rep. Weisz**	P				
Senator Marcellais	P						**Rep. Kilichowski**	P				

Vote Count _____ Yes _____ No _____ Absent

Senate Carrier _____ **House Carrier** _____

LC NO._____._____ of amendment

LC NO._____._____ of engrossment

Emergency clause added or deleted _____

Statement of purpose of amendment _____

Date: 4-23-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2195 as (re) engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
- ☐ HOUSE recede from House amendments and amend as follows

Senate/House Amendments on SJ/HJ pages(s) _____--_____

- ☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) _____ was placed on the Seventh order of business on the calendar.

Motion Made By _____ Seconded By _____

Senators				Yes	No		Representatives				Yes	No
Senator Erbele	P						**Rep. Porter**	P				
Senator J. Lee	P						**Rep. Weisz**	P				
Senator Marcellais	P						**Rep. Kilichowski**	P				

Vote Count _____ Yes _____ No _____ Absent

Senate Carrier _____ **House Carrier** _____

LC NO._____._____ of amendment

LC NO._____._____ of engrossment

Emergency clause added or deleted _____

Statement of purpose of amendment _____

90216.0104
Title.0300

Prepared by the Legislative Council staff for
Senator Erbele
April 24, 2009

4/24/10c

PROPOSED AMENDMENTS TO SENATE BILL NO. 2195

That the House recede from its amendments as printed on page 932 of the Senate Journal and page 1010 of the House Journal and that Senate Bill No. 2195 be amended as follows:

Page 1, line 1, after "reenact" insert "subsection 3 of section 23-06.6-13 and"

Page 1, line 2, after the first "to" insert "revisions and"

Page 1, after line 3, insert:

"**SECTION 1. AMENDMENT.** Subsection 3 of section 23-06.6-13 of the North Dakota Century Code is amended and reenacted as follows:

3. When a hospital refers an individual at or near death to a procurement organization, the organization may conduct any reasonable examination necessary to ensure the medical suitability of a part that is or could be the subject of an anatomical gift for transplantation, therapy, research, or education from a donor or a prospective donor. During the examination period, measures necessary to ensure the medical suitability of the part may not be withdrawn unless the hospital or procurement organization knows that the individual expressed a contrary intent or the measures are contrary to reasonable medical standards."

Page 2, line 4, after the underscored period insert "If involved in resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs as stated orally or as contained in the declaration or advance health care directive."

Page 2, line 5, after the underscored period insert "If the conflict is not resolved expeditiously, the direction of the declaration or advance directive controls."

Page 2, line 10, replace "contraindicated" with "contrary to reasonable medical standards"

Page 2, line 11, remove "by appropriate end-of-life care"

Renumber accordingly

Date: 4-24-09

Roll Call Vote #: _____

2009 SENATE CONFERENCE COMMITTEE ROLL CALL VOTES

BILL/RESOLUTION NO. SB 2195 as (re) engrossed

Senate Human Services Committee

☒ Check here for **Conference Committee**

Action Taken
- ☐ SENATE accede to House Amendments
- ☐ SENATE accede to House Amendments and further amend
- ☐ HOUSE recede from House Amendments
- ☒ HOUSE recede from House amendments and amend as follows

Senate (House) Amendments on (SJ)/HJ pages(s) 932 --_____

- ☐ **Unable to agree**, recommends that the committee be discharged and a new committee be appointed.

((Re)Engrossed) 2195 was placed on the Seventh order of business on the calendar.

Motion Made By Rep. Porter Seconded By Rep. Kilichowski

Senators				Yes	No		Representatives				Yes	No
Senator Erbele	P			✓			Rep. Porter	P			✓	
Senator J. Lee	P			✓			Rep. Weisz	A				
Senator Marcellais	P			✓			Rep. Kilichowski	P			✓	

Vote Count 5 Yes 0 No 1 Absent

Senate Carrier Sen. Erbele **House Carrier** Rep. Porter

LC NO. 90216 . 0104 of amendment

LC NO. _____ . _____ of engrossment

Emergency clause added or deleted _____

Statement of purpose of amendment _____

REPORT OF CONFERENCE COMMITTEE

SB 2195: Your conference committee (Sens. Erbele, J. Lee, Marcellais and Reps. Porter, Weisz, Kilichowski) recommends that the **HOUSE RECEDE** from the House amendments on SJ page 932, adopt amendments as follows, and place SB 2195 on the Seventh order:

That the House recede from its amendments as printed on page 932 of the Senate Journal and page 1010 of the House Journal and that Senate Bill No. 2195 be amended as follows:

Page 1, line 1, after "reenact" insert "subsection 3 of section 23-06.6-13 and"

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Page 1, after line 3, insert:

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Page 2, line 10, replace "contraindicated" with "contrary to reasonable medical standards"

Page 2, line 11, remove "by appropriate end-of-life care"

Renumber accordingly

SB 2195 was placed on the Seventh order of business on the calendar.

2009 TESTIMONY

SB 2195

#1

Testimony in Favor of Senate Bill 2195
Senate Human Services Committee
January 19, 2009

Chairman Lee, Members of the Committee:

I'm Gail Hagerty, a district judge in Bismarck. I'm also a Uniform Law Commissioner and had the privilege of serving on the drafting committee for the Uniform Anatomical Gift Act which was adopted by the legislature in 2007. I am convinced the action you took during the last session has saved lives.

During the closing days of the legislative session, we learned there was an amendment to the Uniform Act intended to address concerns about medical ethics when there is a conflict between an advanced health care directive and the desire to make an anatomical gift. At that point, we decided to present the amendment to you during the 2009 session. I know Bruce Levi will explain the conflict and how it is best resolved.

This bill addresses the problem in the correct manner and adopting it will allow us to move forward with a law that is uniform.

I respectfully request your support of Senate Bill 2195.

Her name was Alexa.

She was 14 and from West Fargo. She died waiting for a double lung transplant.

She was one of 11,000 in America who dies every year waiting for an organ donation.

None of us want to think of something tragic happening to us, but if it did, wouldn't it be better if it gave others the chance to live.

Our legislature has now made it possible for people as young as 14 to be listed on their driver's license or permit as an organ donor. Just check the box on your license or permit application and tell your family.

Scouting for Life

Youth talking to youth about saving lives.

For more information, go to:
www.ScoutingforLife.org

Scouting for Life is a project of the Order of the Arrow, Scouting's national honor society.

NORTH DAKOTA MEDICAL ASSOCIATION

1622 East Interstate Avenue
Post Office Box 1198
Bismarck, North Dakota
58502-1198

(701) 223-9475
Fax (701) 223-9476

Testimony in Support of Senate Bill No. 2195
Senate Human Services Committee
January 19, 2009

Madam Chairman Lee and members of the Committee. I'm Bruce Levi and I serve as the Executive Director of the North Dakota Medical Association. The North Dakota Medical Association is the professional membership organization for North Dakota physicians, residents and medical students.

SB No. 2195 addresses the need for an appropriate balance between respecting wishes about end-of-life care and organ donation. The North Dakota Medical Association supports both organ donation and quality end-of-life care. They are not mutually exclusive considerations in most cases. This bill recognizes that in appropriate cases *and with permission*, briefly continuing life support to enable organ donation may allow an important end-of-goal of the patient to be achieved.

Late last legislative session, the amendment to the Revised (2006) Uniform Anatomical Gift Act made on March 27, 2007, by the National Conference of Commissioners on Uniform State Laws was raised and it was agreed to defer the issue until this legislative session. A criticism of Section 21 of the Revised (2006) Uniform Anatomical Gift Act, now codified at NDCC Section 23-06.6-20, was that the 2006 Act allowed donation to supersede other end-of-life care considerations.

The amendment to Section 21 of the 2006 UAGA now recognizes that organ donation consideration is one part of end-of-life care and states clearly that organ donation should not interfere with quality end-of-life care. The conflict resolution approach embraced in SB No. 2195 is a reasonable approach, in our view, that accommodates both organ donation and end-of-life care considerations.

As has been the case previously in our state with both organ donation and advance care planning legislation, this bill raises the professional imperative that physicians and hospitals fulfill their responsibilities to educate patients on our state's new health care directive law and anatomical gift law and encourage patients to expressly document their preferences about the use of life support systems for organ donation at the end-of-life.

Our recently revised (2005 and 2007) health care directive law facilitates the likelihood that a North Dakota patient will expressly address the use of life support systems for organ donation by including a specific provision relating to anatomical gifts in the statutory health care directive form (NDCC 23-06.5-05.1(5) and 23-06.5-17), thereby encouraging consideration of any potential conflict.

Thank you for the opportunity to testify on behalf of the North Dakota Medical Association. We urge a "Do Pass" on SB No. 2195.

Caring for Organs or for Patients? Ethical Concerns about the Uniform Anatomical Gift Act (2006)

Michael A. DeVita, MD, and Arthur L. Caplan, PhD

In 2006, the National Conference of Commissioners on Uniform State Laws rewrote the Uniform Anatomical Gift Act. To overcome the problem of family members prohibiting organ donation from their deceased loved ones even when a donor card existed, the commissioners modified the act to prevent end-of-life care from precluding organ donation. An unintended consequence of the new wording creates the potential for end-of-life care that prioritizes care of the potential donor organs over care and comfort of the dying person. The commissioners have now revised the act, but the original version has already been legislated in many states, with others poised to follow. To protect dying patients' wishes about their end-of-life care, states that have legislated or are considering the original act must replace it with the revised version. A long-term and important ethical precept must stand: Care of dying patients takes precedence over organs. Another laudable goal must be promoted as well: Organ donation is an important part of end-of-life care.

Ann Intern Med. 2007;147:876-879. www.annals.org
For author affiliations, see end of text.

A man has a stroke and has irreversible brain injury, but he is not brain dead. The family want to honor his wishes to "not be kept alive on machines if there is no hope," something he put into an advance directive. However, he designated himself as a donor on his driver's license. The physician wants to discuss what to do next, and how to prioritize care, but he is stopped by a new state law, modeled after the new Uniform Anatomical Gift Act (2006). The law states that, because the patient is an organ donor, his end-of-life care must be managed in a way to promote donation, even if it compromises comforting care. His do-not-resuscitate order is reversed, and he is resuscitated when he becomes hypotensive and loses pulse. Mechanical ventilation, blood sampling, and other critical care are continued. The physician cannot discuss options, because according to the Organ Procurement Organization, the family does not have the option not to donate. Therefore, any decisions regarding terminating critical care are vetoed per statute. Twelve hours later, the patient is taken to the operating room, life-sustaining treatments are removed, he dies, and his organs are procured.

This is a true story. We believe it represents an unintended consequence of new language incorporated into the Uniform Anatomical Gift Act (2006).

The Uniform Anatomical Gift Act

Recently, the National Conference of Commissioners on Uniform State Laws (NCCUSL) made important and needed revisions to the Uniform Anatomical Gift Act (2006) (1), the key model statute used by every state as the legal foundation for organ and tissue donation. In the process of making needed changes, however, they created model legislation containing serious ethical problems. In the model act, the NCCUSL urged state legislatures to create a law that gave organ donation priority over a person's advance directive regarding their end-of-life care and physician orders for life-sustaining treatment (2, 3). The prioritization was ethically improper and will probably be counterproductive to the Commissioners' laudable intent, which was to increase the number of organ donors. Eighteen states have already adopted the statute, 3 have had it passed by at least 1 house of the state legislature, and another 9 have introduced it into their legislatures for action (Table 1). After the Uniform Anatomical Gift Act (2006) was challenged by ethicists (4), the NCCUSL amended the offending section with ethically more acceptable language (Table 2). Despite these changes, ethically suspect laws are already in place. Whether they are changed remains to be seen.

The story of the Uniform Anatomical Gift Act (2006) and the last-minute attempt to modify it provides important insights into controversies surrounding organ donation and end-of-life care. In this article, we outline the reason for updating the act; the ethical concerns involved; and what we can learn from the failure of expert, ethical, and well-meaning people to recognize an important and long-standing ethical boundary. We raise this issue out of a concern that the desire for donor organs has become so fervent that obvious ethical transgressions were overlooked in the effort to improve the process.

The Uniform Anatomical Gift Act needed to be updated. First written in 1968 and revised in 1987 (5), the 1987 model statute was adopted by only 25 states (1), leaving the United States without a national standard. It also needed to be clearer and stronger regarding an individual's decision to donate his or her organs after death, especially in protecting patients' wishes to donate their organs against the wishes of others. The authors of the 2006 version achieved those goals.

See also:
Print
Key Summary Points 877
Web-Only
Conversion of graphics into slides

Unfortunately, the original Section 21 in the 2006 version did more. In aiming to prevent advance directives from precluding organ donation, it prioritized the donation of organs over the patient's other end-of-life wishes, as well as physician orders for limitation of life-sustaining treatments. As originally written, Section 21 could have been used to *prevent* provision of routine end-of-life care by patients' bedside physicians, nurses, and allied health professionals in the interest of organ preservation. The proposal (1) stated:

> If a prospective donor has a declaration or advance health-care directive, *measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor,* unless the declaration expressly provides to the contrary [emphasis added].

Key Summary Points

The Uniform Anatomical Gift Act (2006) is improved, but it prioritizes organ donation over end-of-life care concerns. This is ethically wrong.

The original Uniform Anatomical Gift Act (2006) has been legislated in many states.

A revised Uniform Anatomical Gift Act (2006) corrects the concerns but has not been introduced into most legislation.

Health professionals should urge states to adopt the revised Uniform Anatomical Gift Act (2006).

Promoters of organ donation should include more end-of-life and critical care professionals in their organizations.

Unintended Consequences of the Uniform Anatomical Gift Act (2006)

This statement and the commentary that followed assume that someone wishing to be a donor has prioritized organ donation over other end-of-life management considerations (such as decisions to decline endotracheal intubation, cardiopulmonary resuscitation, and mechanical ventilation). The assumption that would-be organ donors want to prioritize donation over routine palliative care lacks empirical support. There is no evidence that persons prioritize organ donation above (or below, for that matter) other end-of-life care. This assumption also contrasts with a broad literature regarding patients' desires to have their preferences for end-of-life care followed (6). The wording of Section 21 permitted a patient with respiratory failure after a neurologic event to have unwanted intubation "to ensure the medical suitability of an organ for transplantation" even if the patient had an advance directive to the contrary, because "... therapy may not be withheld or withdrawn from the prospective donor, unless the declaration expressly provides to the contrary" (1).

When the original version of the Uniform Anatomical Gift Act (2006) became law, patients were put at risk. To be sure, a person's advance directive could avoid this conflict by stating not only which specific treatments are not wanted but also *specifying the priority* of organ donation and end-of-life care. This has the advantage of providing caregivers with explicit first-person instructions. However, those with a donor card who fail to prioritize their wishes will have their advance directive for withholding or withdrawing life support nullified.

The original version of the Uniform Anatomical Gift Act (2006) created an unwanted and improper intrusion into the physician's care of dying patients because, if enacted by states, it legislates the countermanding of a physician's orders by other personnel, namely organ procurement coordinators, who are not licensed to prescribe for or provide medical care for living individuals. A national initiative is under way to increase use of physician orders for life-sustaining treatment to promote appropriate end-of-life care (2, 3). Physician orders for life-sustaining treatment are not patient wishes; they are a physician's order set. Physicians' orders have a protected status in a health care organization, and rightly so. Imagine the potential for harm if physicians' orders were construed merely as suggestions that could be ignored in the service of broader social purposes. Sometimes physicians do improperly write orders that have the effect of precluding organ donation. But, ignoring physicians' orders regarding end-of-life care is not the best method to rectify physicians' errors or increase trust between intensive care unit caregivers and organ procurement professionals.

Evidence indicates that people have clear opinions on their end-of-life care, including not only preferences for interventions, such as palliative medications, but also organ donation (7). However, individuals rarely record their priorities in their advance directives. Regrettably, no one, when asked for consent to donate (which often occurs at a state motor vehicle license office), is also asked whether the organ donation should nullify their preferences regarding end-of-life care. In this setting, the argument that organ donor consent should take precedence over all other end-of-life care issues is at least dubious, possibly against the patient's wishes, and definitely uninformed. Acting on such uninformed consent is ethically and perhaps legally improper (because of a lack of evidence that people understand this issue when consent is obtained). And yet, it happens. The Uniform Anatomical Gift Act (2006) took advantage of this broad, uninformed consent and undefined prioritization to indeed make donation take priority over other end-of-life care considerations.

The original version of the Uniform Anatomical Gift Act (2006) is unethical in another way. Because it vetoed certain routine end-of-life orders written by physicians, the

Table 1. Status of the Uniform Anatomical Gift Act (2006) in the United States, as of August 2007*

Enacted	Passed 1 or Both Legislatures and Are Awaiting Governor's Signature	Introduced into Legislature, Action Pending
Arizona†	California	District of Columbia
Arkansas	North Carolina	New Jersey
Colorado†	Texas	New York
Idaho		U.S. Virgin Islands
Indiana		Alabama
Iowa†		Alaska
Kansas		Maine
Minnesota†		Missouri
Montana		Washington
Nevada†		
New Mexico		
North Dakota		
Oregon†		
Rhode Island‡		
South Dakota		
Tennessee†		
Utah		
Virginia		

* Information from the National Conference of Commissioners on Uniform State Laws, August 2007. Accessed at www.nccusl.org/update/uniformact_factsheets/uniformacts-fs-uaga.asp on 22 October 2007.
† These states enacted the revised Uniform Anatomical Gift Act (2006).
‡ Section 21 was omitted.

2006 act can subordinate care of the patient to care of the organ. Priority care for organs makes sense for individuals who already have been determined to be dead according to neurologic criteria, but not when patients are still alive. There is a clear proscription against transplantation personnel caring for potential donors because of the conflict of interest. The 2006 act codifies exactly this behavior. There is no question that the best policy for patients who are alive in intensive care units is continued care by the critical care professionals rather than organ procurement organization representatives or transplantation physicians. After patient death, the latter 2 may take control.

Finally, this inversion of priorities may be counterproductive to the goal of increasing organ availability. A known barrier to obtaining consent for organ donation from individuals is the fear that the consent will lead to poor critical care because decisions might be based on what is best for organs rather than what is best for the patient (8, 9). Put bluntly, people are afraid that their doctors (critical care or otherwise) will stop appropriate care to "get at" their organs. The original version of the Uniform Anatomical Gift Act (2006) seemed to codify this improper behavior.

We know of at least 1 organ procurement organization representative who told a physician he could not discuss prognosis and end-of-life treatment options with a patient's family because the patient had a donor designation on his driver's license "and withdrawing treatment is not an option." The representative had the concern that the family would choose to withdraw life-sustaining treatments after the discussion and nullify the donor's intent to donate. Families cannot revoke a person's documented decision to be an organ donor. But the notion that the veto power implicitly created by the new act might be misused to prevent physicians from discussing options concerning prognosis and treatment can only *increase* distrust of the organ donation process.

Lessons Learned

Of course, organ and tissue donation should occur whenever possible as part of quality end-of-life care. If organ donation cannot occur because of patient wishes for specific end-of-life care, it should sadden us. But we may take consolation in the fact that tissues—eyes, skin, bones, ligaments, heart valves, and blood vessels—can be donated and still save many lives. For some, that will have to do. For others, organ donation may be a higher priority, and they might want to adjust their care in order to achieve that goal. But of course, sound public policy would require us to ask them.

Those who do want to donate should do 1 of 3 things: 1) Put this decision into their advance directive; 2) notify their local organ procurement organization to enter them into their donor registry; or 3) for states that have legislation to support it, designate themselves as a donor when they obtain their driver's license. In addition, for the people who wish to prioritize organ donation over routine end-of-life care, this should be indicated in their advance directive.

What should happen? First, we must protect patients. States that haven't introduced the Uniform Anatomical Gift Act (2006) should introduce the amended version. States that have introduced the original version should

Table 2. Changes to Text of Section 21

Original wording of Section 21

b) If a prospective donor has a declaration or advance health-care directive, *measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor,* unless the declaration expressly provides to the contrary [emphasis added].

Revised wording of Section 21

b) If a prospective donor has a declaration or advance health-care directive and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, an agent acting under the prospective donor's declaration or directive, or, if none or the agent is not reasonably available, another person authorized by law other than this [act] to make health-care decisions on behalf of the prospective donor, shall act for the donor to resolve the conflict. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under Section 9. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.

abandon it in favor of the revision. Finally, states that have already enacted the original version must amend the law with the new Section 21 as soon as possible to protect their citizens. It is important that our laws reflect our intention to provide outstanding end-of-life care as a priority and that organ donation should not trump that intention.

Second, there are some important lessons to be learned. It is likely that most of the time, critical care professionals can satisfy patient wishes concerning both how they die and their desire to donate organs, particularly given the widespread availability of donation after cardiac death. It is a mistake to think that prioritizing 1 over the other is likely to foster both. We are pleased that, for the first time, wording has been added to the revised Uniform Anatomical Gift Act (2006) reflecting the important notion that organ donation should not adversely affect palliative care in a significant way. There is a sort of "dual universe" that exists at the bedside of dying patients who also want to be organ donors. On the one hand, critical care professionals want to provide quality end-of-life care. On the other, procurement coordinators try to promote organ donation activities that can save lives. In the real world, these goals can be seen as competing interests and can raise suspicions that undermine trust. The revised wording helps to resolve the ambiguity and misperceptions.

Third, NCCUSL and other organ donation groups must broaden representation to include end-of-life caregivers. Neither NCCUSL nor organ procurement organizations are insensitive to the terminally ill or their families. Of course, they too want to promote quality end-of-life care. But the NCCUSL drafting committee, which seems to have had no representation by end-of-life care experts, disregarded important ethical concerns. We believe that their membership reflects, and perhaps promotes, the same sort of dichotomy that exists at the bedside, as well as the "let's increase donation" mindset that led to this misguided section. In the future, those concerned with organ donation must work closely with those involved with end-of-life care to create laws and public policies that avoid oversights and unanticipated concerns about that care. We, like the Institute of Medicine (10), urge expanded membership in all organ donation policy discussions.

Fourth, organ donation is an end-of-life care issue. People choose to donate at least in part because they want saving lives to be part of their legacy. New organ donor collaboratives recognize this and are aimed at critical care professionals who are integral to the process. We applaud this partnership. Perhaps it is time to stop promoting organ donation by using a "we need your organs" strategy. Instead, the story of the Uniform Anatomical Gift Act (2006) suggests the wisdom of a strategy that includes end-of-life caregivers and says, "After you die, organ donation can add to a legacy you and your family can treasure." Great end-of-life care is a necessary foundation to promote trust that may overcome long-existing anxieties some have toward organ donation.

CONCLUSION

Should organ donation trump end-of-life care? If we know this is the patient's wish, then yes. In other situations, we think not. Donor registry permission should emerge as an authoritative voice regarding patient wishes only *after* end-of-life care decisions have been resolved. If done in this order, no change in donor registries is required. The revised Uniform Anatomical Gift Act (2006) makes this point. We advocate that for people who do enter into a registry, they receive communication (perhaps a pamphlet) regarding what their designation means and how to make modifications to their decision. This would address concerns that the current process does not provide *informed* consent. But this recommendation should not distract from our main point: In a situation where the priority is not known, we should always err on the side of taking care of patients before organs.

From University of Pittsburgh, Pittsburgh, and University of Pennsylvania, Philadelphia, Pennsylvania.

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Requests for Single Reprints: Michael A. DeVita, MD, University of Pittsburgh Medical Center Presbyterian Hospital, Room C-111, 200 Lothrop Street, Pittsburgh, PA 15213.

Current author addresses are available at www.annals.org.

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Same handout given to House.

NAAGazette
January 18, 2008

NEWS & EVENTS

For media inquiries and other press-related questions, please contact the NAAG Press Center at (202) 326-6027.

NAAGazette

END-OF-LIFE CARE AND ORGAN DONATION: IS THERE AN IRRECONCILABLE CONFLICT?

Judy McKee, End of Life Health Care Project Coordinator and Counsel

Recently, I had to renew my Virginia driver's license. I suppose this is one of those experiences that is shared with the majority of the population of the United States over the age of 16. A visit to the DMV is an equalizer; everyone has to wait; everyone fidgets; everyone either scowls or looks sympathetically at the young mother trying to control her three pre-school children. The distinguished gentleman sitting next to me was a recent immigrant from Uganda. As he was filling out his form, I noticed he stopped and looked quizzically at the question that is on most states' driver's license applications. Did he wish to be an organ donor? He turned to me, "Why do they ask this question? Is driving here so dangerous? Will they just cut me open and take whatever they want?"

The 1987 Uniform Anatomical Gift Act (UAGA) authorized the registering of organ donors via drivers' licenses. Until this later version was adopted, states that had enacted the 1968 version of the UAGA required that gifts of organs be effected in the same manner as wills. By the 1980s, it had become clear that the increasing success rate of organ transplants, enabled by modern immunosuppression and more sophisticated surgical techniques, required the donation of more organs. Surveys had shown that most Americans were comfortable with the concept of organ transplantation, but that few had registered to donate their organs. The idea that licensed drivers could indicate their desire to be organ donors on drivers' licenses was an innovative way to allow many more Americans to more easily give the "gift of life."

Even with the driver's license alternative, however, the need for transplantable organs has remained high. As of the first day of 2008, 98,033 people were awaiting organ donations.[1] Of this number, about

19 will die each day awaiting a transplant.[2] Most of the organs currently donated come from deceased donors. Seven organs can be taken for transplantation: the heart, lungs, liver, pancreas, two kidneys and the small intestine. In addition, a donor can give their eyes and numerous tissues, including bone.[3]

To address the still-critical shortage of organs, a panel of the National Conference of Commissioners on Uniform State Laws (NCCUSL) spent several years conferring with ethicists, lawyers, physicians, and other stakeholders to draft another version of the UAGA that would hopefully make more organs available for transplant. Preliminary research by the Association of Organ Procurement Organizations had revealed that state laws diverged on many issues and that there were choice-of-law and conflict-of-law issues that should be resolved to ease organ donation. Another problem discovered was that, under the earlier UAGA, healthcare agents were not authorized to make post-mortem organ donations. In addition, under the then-existing UAGA, one family member could veto a donation that the remaining family members wished to make.

The Revised Uniform Anatomical Gift Act of 2006 was approved by the NCCUSL in July 2006. The act expanded the list of people who could consent to an unconscious patient becoming a donor and made it clear that a person's expressed decision to be an organ donor could not be revoked by anyone else. It provided for the making of an anatomical gift on a registry as well as via a driver's license or a donor card. The revised act also authorized the gift of organs by any member of a class who was reasonably available if he or she were unaware of an objection by another member of that class. Other features of the act were designed to increase organ, tissue and eye donations.

Unfortunately, however, in the laudable effort to increase the number of available organs for transplant, the drafters of the 2006 act created an ethical issue for those providing end-of-life care. Under the act, unconscious patients who had signed donor cards but had also signed documents stating that they did not want ventilator or other care that would keep them alive would find their end-of-life care wishes trumped by the revised UAGA. Under the 2006 UAGA, the donor card has priority over the wishes expressed for end-of-life care; the act requires that all care necessary must be given to keep a patient's organs viable until a transplant can take place.

In a recent article in the *Annals of Internal Medicine,* [4] the authors recount the horrific story of a patient who had a stroke and suffered irreversible brain injury. He had signed an advance directive that he not be kept alive by machines if there were "no hope." He had also agreed to be an organ donor on his driver's license. Under the 2006 version of the UAGA that the state had adopted, the man's physician could not provide palliative care but, instead, had to reverse the patient's do-not-resuscitate order and manage his end-of-life care to promote donation, not to provide comforting care to the dying man.

The assumption evidently made by the drafters of the 2006 UAGA was

that a donor would prioritize organ donation over palliative care. Section 21 of the act permitted a patient with respiratory failure, for instance, to have unwanted intubation "to ensure the medical suitability of an organ for transplantation" — even if the patient had a signed advance directive expressly rejecting such therapy — because " . . . therapy may not be withheld or withdrawn from the prospective donor" unless the advance directive expressly provided for such withholding.[5] It is a rare advance directive that records a patient's priorities concerning palliative care versus organ donation.

To address this ethical minefield, the Commissioners approved revised wording for section 21.[6] Under this revised wording, if there is a conflict between the express wishes for end-of-life care and maintaining the viability of an organ for transplant, the patient-donor and the physician must confer to resolve that conflict. If the patient is incapacitated (a most likely scenario), then a patient's agent, if there is one and if "reasonably available," must resolve the conflict. Otherwise, "another person authorized by law other than" the UAGA will be asked to make that decision. The section continues that the conflict must be resolved as expeditiously as possible. And, finally, "Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care."

Unfortunately, many states that enacted the 2006 UAGA have not enacted the revised language for section 21.[7] Moreover, this potential conflict between organ donation and end-of-life care in accordance with one's wishes has not been generally publicized. It is ironic to think that the very law that was written to promote organ donation might, in fact, backfire if potential donors become aware that, in some states, organ donation is more important than providing end-of-life care in accordance with one's wishes. Such a law feeds the concern of many potential donors that their organs will become more important than they are themselves as they near the end of their lives.

To ease this fear and to help accomplish the purpose that drove the enactment of the 2006 UAGA, states that enacted the original 2006 UAGA may wish to enact the revised version in their upcoming legislative sessions. In addition, in preparing advance directives, potential organ donors should be encouraged to express their own desires as to how they wish to prioritize care.

My conversation with the gentleman from Uganda ended with his agreeing to be a donor. Certainly, we should encourage organ donation as a gift that is the most intimate and life-affirming as any that could be given. However, we should also insist that our laws support our wishes and desires as to the type and intensity of care we receive at the end of our lives.

[1] United Network for Organ Sharing (UNOS) (visited Jan. 1,2008) (http://www.unos.org).

[2] U.S. Dep't of Health and Human Servs., Health Resources and Servs. Admin. Healthcare Sys. Bureau, Div. Of Transplantation (visited Jan. 1, 2008) (http://www.organdonor.gov).

[3] Sheldon F. Kurtz and Christina Woodward Strong, "The 2006 Revised Uniform Anatomical Gift Act—A Law to Save Lives, *Health Law Analysis*, Feb. 2007, at 44.

[4] Michael A. DeVita and Arthur L. Caplan, "Caring for Organs or for Patients? Ethical Concerns about the Uniform Anatomical Gift Act (2006)," 147 *Annals of Int. Med* 876-79.

[5] Revised Uniform Anatomical Gift Act, 2006. The original section 21 read as follows:

b) If a prospective donor has a declaration or advance health-care directive, measures necessary to ensure the medical suitability of an organ for transportation or therapy may not be withheld or withdrawn from the prospective donor, unless the declaration expressly provides to the contrary.

[6] The revised version of section 21 reads as follows:

b) If a prospective donor has a declaration or advance health-care directive and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy, the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, an agent acting under the prospective donor's declaration or directive, or, if none, or the agent is not reasonably available, another person authorized by law other than this [act] to make health-care decisions on behalf of the prospective donor, shall act for the donor to resolve the conflict. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under Section 9. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.

[7] DeVita and Caplan, *supra* note 4, at 878, table 1.

#3

Testimony of Patrick Ward in Support of SB 2195
Senate Human Services Committee
January 17, 2009

Chairwoman Lee and members of the committee. My name is Patrick Ward and I represent LifeSource, the organ and tissue procurement organization for the upper great plains states including North Dakota.

LifeSource supports Senate Bill 2195 to amend the Uniform Anatomical Gift Act as it provides further direction on how to honor and fulfill both an individual's end-life wishes as expressed in an advanced health care directive and simultaneously fulfill opportunities for saving lives through donation. Passage of this amendment will also ensure consistency and uniformity in donation legislation across state lines.

The existing language was written with the goal of eliminating any potential conflict between end-of-life wishes and opportunities for organ and tissue donation. Section 23-06.6-20 provides guidance on how to resolve this situation by requiring involvement of the physician, donor or their family, and the procurement organization in the process.

This legislature adopted the revised UAGA in 2007. The North Dakota legislature passed this act with the goal of further advancing organ and tissue donation in the State of North Dakota. In passing this legislation this legislature respected the importance of uniformity so there is consistency in the donation process between states across state lines and passed the original language with only minimal amendments.

In the midst of the 2007 Legislative Session the Standby Committee for the Uniform Anatomical Gift Act recommended an amendment to Section 21 of the Act. North Dakota was unable to include this amendment as the legislation had already been passed by the legislature. Senate Bill 2195 simply amends the Uniform Anatomical Gift Act in keeping with the amendment put forward by NCCUSL.

We urge you give Senate Bill 2195 a unanimous do pass recommendation. Thank you.

#4

North Dakota Catholic Conference

Representing the Diocese of Fargo and the Diocese of Bismarck

Christopher T. Dodson
Executive Director and
General Counsel

To: Senate Human Services Committee
From: Christopher T. Dodson, Executive Director
Subject: Senate Bill 2195
Date: January 19, 2009

The North Dakota Catholic Conference opposes Senate Bill 2195.

The Catholic Church strongly encourages organ donation. In Catholic teaching, organ donation after death is a noble and meritorious act and an expression of solidarity. The Catholic Health Care Directive published by the North Dakota Catholic Conference has a section whereby people can state their request to make an anatomical gift. Last year, the conference sponsored a day-long workshop on organ donation and transplantation.

So it is not from an attempt to discourage anatomical gifts that we oppose SB 2195. Indeed, is it with the hope of *not* discouraging organ donation that we oppose SB 2195.

In order for the public to accept and participate in organ donation -- as well as to be ethically acceptable -- donations must be made with informed consent and in a manner consistent with the donor's religious and moral beliefs. This is the case with all health care procedures.

This legislative body has determined that whenever a person with a health care directive cannot speak for himself or herself, the person's health care directive prevails. Senate Bill 2195 would change this policy by placing potential anatomical gifts at the same level as a health care directive. The directive would no longer prevail. Instead, it forces the parties to resolve conflicts between the health care directive and the potential donation. In fact, lines 8 - 11 on page 2 of the bill go further, allowing procedures to be taken pending resolution of the conflict, even if they contradict the health care directive. This, in effect, gives priority to the potential anatomical gift, radically altering existing law.

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This change has real consequences. Some measures used to enhance medical suitability of organs and tissue for transplantation raise serious ethical questions that have not been, and may not be, resolved. Like all health care procedures, these questions should be resolved in favor of the person's health care directive.

Failure to respect and give priority to health care directives could ultimately undermine the Uniform Anatomical Gift Act's purpose of fostering anatomical gift donation. Health care directives are the primary means by which a person indicates their health care wishes and the religious and moral beliefs that should guide and limit health care decisions. This principle guided us during years of work to improve and encourage the use of health care directives.

In the many workshops I have given on health care directives in North Dakota, one of the most commonly expressed reservations about executing a directive is concern that a physician's wishes or interpretation of directive would prevail over the beliefs and principles set out in the directive. Similarly, a common concern about organ donation is that it will be done in a manner contrary to a person's religious beliefs. In both cases, I have assured people that under the law, the health care directive prevails. Should this bill pass, I could no longer provide that assurance.

By elevating procedures to facilitate organ donation to the same level - or to a greater level - than health care directives, Senate Bill 2195 risks removing the sense of security people need before they will execute health care directives or make organ donations. Thus, in addition, to creating ethical problems, SB 2195 threatens the work so many have done to encourage both organ donation and health care directives.

We respectfully request a **Do Not Pass** recommendation on Senate Bill 2195.

A Guide to Health Care Directives

A Resource from the North Dakota Catholic Conference

Health Care Directives give instructions for future health care decisions. To assist people who wish to have a health care directive, the North Dakota Catholic Conference has prepared a Catholic Health Care Directive that meets the state's legal requirements, expresses Church teaching, and reflects the recommendations of church, health care, and community leaders. This Guide answers some basic questions about the law, Church teaching, and completing a health care directive.

What do all these terms mean?

A "**living will**" usually means a document in which a person states *only* his or her health care wishes. A "**durable power of attorney for health care**" usually means a document in which a person appoints someone to make health care decisions on his or her behalf. "**Advance directive**" usually means a living will, a durable power of attorney for health care, or a combination of the two. "**Health care directive**" is what North Dakota state law calls any advance directive. A "**health care agent**" is what state law calls the person appointed through a health care directive to make health care decisions for another.

Why would I want a health care directive?

A health care directive can help make sure that your health care wishes are followed when you cannot speak for yourself. In addition, a health care directive can help your family and friends during what may be a difficult time.

What happens if I don't have a health care directive?

In North Dakota, if you have not appointed a health care agent and you are unable to make or communicate health care decisions, state law determines who makes health care decisions for you. The law authorizes persons in the following categories, *in the order listed*, to make decisions: your health care agent unless a court specifically authorizes a guardian to make decisions for you, your court-appointed guardian or custodian, your spouse, any of your children, your parents, your adult brothers and sisters, your grandparents, your adult grandchildren, and an adult friend or close relative. No one in a lower category may make the decision if someone in a higher category has refused to consent.

When making a health care decision, the authorized person must determine whether you would consent to the care if you were able to do so. If the person is unable to make this determination, he or she may only consent to the proposed health care if it is in your best interests.

Do I need to use a special form?

No. North Dakota law has an *optional* health care directive form, but many other forms exist that meet the state's legal requirements. In fact, you do not have to use a pre-printed form.

Any written statement that meets these requirements is valid in North Dakota:

- States the name of the person to whom it applies;
- Includes a health care directive, the appointment of an agent, or both;
- Is signed and dated by the person to whom it applies or by another person authorized to sign on behalf of the person to whom it applies;
- Is executed by a person with the capacity to understand, make, and communicate decisions; and
- Contains verification of the required signature, either by a notary public or by qualified witnesses.

If you are Catholic, the North Dakota Catholic Conference suggests that you use the *Catholic Health Care Directive* form. If the form is not included with this document, you can get one by calling the conference at 1-888-419-1237 or by downloading it at *ndcatholic.org*.

Do I need an attorney? What will this cost?

No. It is not necessary to have an attorney provide or fill out the form. However, you should contact an attorney if you have legal questions regarding advance care planning. Health care directive forms are available at no cost from a number of sources, including the North Dakota Catholic Conference.

Should I appoint a health care agent or just write down my wishes?

The North Dakota Catholic Conference recommends that your health care directive include the appointment of a health care agent.

Written instructions alone are only as good as your ability to accurately predict every possible future medical condition and every future medical treatment option. This is an almost impossible task. In addition, without a health care agent, the person interpreting those instructions might be someone who does not truly know what you wanted.

By appointing a health care agent, you can make sure that someone who cares about you will apply your wishes and personal beliefs to the health care choices at hand – just as you would do. Even if you appoint a health care agent, you can still give written health care instructions to direct, guide, and even limit the actions of your agent.

Why does the hospital always ask if I have a living will? Do I have to have one?

Federal law requires health care providers to ask you if have an advance directive. By habit, they often use the term "living will." You are not required to have any advance directive and you do not have to use the form they provide.

Who can be my health care agent?

In North Dakota, your agent must be 18 years of age or older and must accept the appointment in writing. Talk beforehand to the person you wish to appoint. Find out if the person is willing to accept the responsibility. Tell the person about your wishes and preferences for care. Be sure the person is willing and able to follow your wishes.

I already have an advance directive. Do I need to do a new one? What if I want a new one?

Valid advance directives completed under the old law (before August 1, 2005) will still be honored. *Validly executing a new health care directive automatically revokes any older advance directive.* Inform everyone who might have a copy of that old document that it is no longer valid and that you have a new health care directive.

On health care directive forms, who is the "principal," "declarant," and "agent?"

You, the person executing a health care directive, are the "principal." When verifying your identity before a witness or notary public, you are also the "declarant." The person you appoint as your health care agent is the "agent."

Will an advance directive that I completed in another state be accepted in North Dakota?

Yes, so long as it complies with the laws of that state and is not contrary to certain North Dakota laws, such as the law against assisted suicide.

Will a health care directive that I completed in North Dakota be accepted in another state?

Most states have reciprocity statutes that give recognition to advance directives completed in other states. Even if a health care directive completed in North Dakota does not meet some of the technical requirements of another state's law, the directive should still be followed since it expresses the your wishes.

What should I do with my health care directive?

Provide a copy of your health care directive to your doctor and any other health care providers such as your hospital, nursing facility, hospice, or home health agency. In addition, you may want to give copies of your health care directive to other persons, such as close family members, your priest, and your attorney, if you have one.

What fundamental principles should guide a Catholic, and indeed any person, who is thinking about health care decisions?

1. *Human life is a precious gift from God.* This truth should inform all health care decisions. Every person has a duty to preserve his or her life and to use it for God's glory.

2. *We have the right to direct our own care and the responsibility to act according to the principles of Catholic moral teaching.* Each person has a right to clear and accurate information about a proposed course of treatment and its consequences, so that the person can make an informed decision about whether to receive or not receive the proposed treatment.

3. *Suicide, euthanasia, and acts that intentionally and directly would cause death by deed or omission, are never morally acceptable.*

4. *Death is a beginning, not an end.* Death, being conquered by Christ, need not be resisted by any and every means and a person may refuse medical treatment that is *extraordinary.* A treatment is extraordinary when it offers little or no hope of benefit or cannot be provided without undue burden, expense, or pain.

5. *There should be a strong presumption in favor of providing a person with nutrition (food) and hydration (water), even if medically assisted.* Providing nutrition and hydration should be considered ordinary care since it serves a life-preserving purpose and the means of supplying food and water are relatively simple and - barring complications - generally without pain. Exceptional situations may exist in which this is not the case, such as when a person is no longer able to assimilate nourishment, or when death is so imminent that withholding or withdrawing food and water will not be the actual cause of death. In no case should food or water be removed with the intent to cause death.

6. *We have the right to comfort and to seek relief from pain.* Although our faith teaches that we can find meaning in suffering, no one is obligated to experience pain. A person has a right to pain relief and comfort care, even if the method or treatment *indirectly* and *unintentionally* shortens life. However, it is not right to deprive the dying person of consciousness without a serious reason.

Is this all there is to know about making ethical health care decisions?

No. These statements are only some basic principles. Some situations, such as pregnancy or organ donation, involve other principles. Understanding and applying these principles to specific cases can be difficult. At times, your bishop or the Pope may provide clarification on the Church's teaching and guidance for specific situations.

For additional resources and information on making ethical health care decisions, contact:

Fargo Diocese Respect Life Office
(701-356-7910)
web site: www.fargodiocese.org

Bismarck Diocese Pastoral Center
(701-222-3035)

North Dakota Catholic Conference
(1-888-419-1237; 701-223-2519)
web site: ndcatholic.org

How can I make sure that decisions made on my behalf are consistent with my Catholic beliefs?

State in your health care directive your desire to have all health care decisions made in a manner consistent with Catholic teaching. The *Catholic Health Care Directive* does this.

Appoint a health care agent who shares your beliefs or, at least, sincerely intends to respect your wishes.

If your health care agent is not familiar with Catholic teaching on these matters, give your agent the name of a priest or lay leader who can provide guidance. You can include the name and contact information of that person in the health care directive. You may also want to give this information to your health care provider.

Are Catholics morally obligated to have an advance directive?

No. However, a health care directive, especially one that appoints a health care agent, is one way to make sure that your care and treatment is consistent with the Catholic faith and your wishes.

Is organ donation morally acceptable? Can I include a donation in my health care directive?

Organ donation after death is a noble and meritorious act and is to be encouraged as an expression of generous solidarity. You should, however, give explicit consent. The *Catholic Health Care Directive* includes an optional section where you can give that consent.

My friend is not Catholic, but likes the Catholic Health Care Directive. Can she cross out the parts that would not apply to her?

Yes, she can. However, it might be a good idea to initial the changes. She can also contact the North Dakota Catholic Conference and we will send you a version of the form that retains the ethical principles in the Catholic Health Directive, but does not contain specific references to the Catholic faith.

How can I make sure my spiritual needs are met?

When you enter a hospital or nursing home, state that you are a Catholic and want to have a priest or lay minister care for your spiritual needs. Also state if you want to see a particular priest. Unless you have done this, certain privacy rules may prevent the hospital or nursing home from informing a priest about your presence or allowing him to visit.

If you cannot communicate your wishes when being admitted, your health care directive and health care agent can to do this for you.

Include spiritual requests in your health care directive. The *Catholic Health Care Directive*, for example, includes a request for the Sacraments of Reconciliation, Anointing, and Eucharist as viaticum, if you are terminally ill. "Viaticum" literally means "food for the journey." Death is not the end. Rather, it is only a "passing over" from this world to the Father. In preparation for this journey, the Church offers Eucharist as viaticum, i.e., Christ's body and blood as food for the journey.

Have more questions?

Need copies of the Catholic Health Care Directive?

Visit the conference web site at: ndcatholic.org. The site includes more questions and answers, forms to download, and places to get more information.

You can also contact the North Dakota Catholic Conference:
701-223-2519
Toll-free at 1-888-419-1237
ndcatholic@btinet.net

A Catholic Health Care Directive

My Health Care Agent

I, _____,
trust and appoint
_____ as my
lth care agent. As my health care agent, this person
n make health care decisions for me if I am unable to
make and communicate health care decisions for myself.

If my health care agent is not reasonably available, I
trust and appoint
_____ as my
health care agent instead.

Health Care Agent Information
Name:_____
Address:_____
Phones:_____
_____
Relationship: _____

Alternate Health Care Agent Information
Name:_____
Address:_____
Phones:_____
_____
Relationship: _____

My Wishes
This is what I want my health care agent - or if I have no health care agent, whoever will make decisions regarding my care - to do if I am unable to make and communicate health care decisions for myself. Most of what I state here is general in nature since I cannot anticipate all the possible circumstances of a future illness. If I have not given specific instructions, then my agent must decide consistent with my wishes and beliefs.

As a Catholic, I believe that God created me for eternal life in union with Him. I understand that my life is a precious gift from God and that this truth should inform all decisions with regards to my health care. I have a duty to preserve my life and to use it for God's glory. Suicide, euthanasia, and acts that intentionally and directly would cause my death by deed or omission, are never morally acceptable. However, I also know that death, being conquered by Christ, need not be resisted by any and every means and that I may refuse any medical treatment that is excessively burdensome or would only prolong my imminent death. Those caring for me should avoid doing anything that is contrary to the moral teaching of the Catholic Church.

❖Medical treatments may be foregone or withdrawn if they do not offer a reasonable hope of benefit to me or are excessively burdensome.

❖There should be a presumption in favor of providing me with nutrition and hydration, including medically assisted nutrition and hydration, if they are of benefit to me.

n accord with the teachings of my Church, I have no moral objection to the use of medication or
edures necessary for my comfort even if they may indirectly and unintentionally shorten my life.

❖If my death is imminent, I direct that there be forgone or withdrawn treatment that will only maintain a precarious and burdensome prolongation of my life, unless those responsible for my care judge at that time that there are special and significant reasons why I should continue to receive such treatment.

❖If I fall terminally ill, I ask that I be told of this so that I might prepare myself for death, and I ask that efforts be made that I be attended by a Catholic priest and receive the Sacraments of Reconciliation, Anointing, and Eucharist as viaticum.

Believing none of the following directives conflicts with the teachings of my Catholic faith or the directives listed above, I add the following directives: *(You do not need to complete this section. If you do, you can use an extra sheet, if needed.)*

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Making an Anatomical Gift (Optional)
So long as it is consistent with Catholic moral teaching, I would like to be an organ and tissue donor at the time of my death. I wish to donate the following (initial one statement):
[ ] Any needed organs and tissue.
[ ] Only the following organs and tissue:

Your Signature (The person making this health care directive) **[*This section must be completed.*]**

I sign this Health Care Directive on _____(date) at _____(city), _____ (state).

_____ *(you sign here)*

If you have attached additional pages to this form, date and sign each of them at the same time you date and sign this form.

*To be valid, this health care directive must be **notarized** or **witnessed** when you sign. **If witnessed:** At least one witness must not be a health care or long-term care provider providing you with direct care or an employee of that provider.*

None of the following may be a notary or witness:
1. A person you designate as your agent or alternate agent;
2. Your spouse;
3. A person related to you by blood, marriage, or adoption;
4. A person entitled to inherit any part of your estate upon your death; or
5. A person who has, at the time of executing this document, any claim against your estate.

Acceptance of Appointment by Health Care Agent

I accept this appointment and agree to serve as a health care agent. I understand I have a duty to act in good faith, consistent with the desires expressed in this document, and that this document gives me authority to make health care decisions for the principal only when he or she is unable to make and communicate his or her own decisions. I understand that the principal may revoke this appointment at any time, in any manner. If I choose to withdraw during the time the principal is competent, I must notify the principal of my decision. If I choose to withdraw when the principal is not competent, I must notify the principal's physician.

_____
(Signature of agent) (date)

_____
(Signature of alternate agent) (date)

Option 1: To be Completed by a Notary Public

In my presence on _____ (date), _____ (name of declarant) acknowledged the declarant's signature on this document or acknowledged that the declarant directed the person signing this document to sign on the declarant's behalf.

_____ My commission expires _____, 20___.
(Signature of Notary Public)

Option 2: To be Completed by Two Witnesses

Witness One:
(1) In my presence on _____ (date), _____ (name of declarant) acknowledged the declarant's signature on this document or acknowledged that the declarant directed the person signing this document to sign on the declarant's behalf.
(2) I am at least eighteen years of age.
(3) If I am a health care provider or an employee of a health care provider giving direct care to the declarant, I must initial this box:[ ].

I certify that the information in (1) through (3) is true and correct.

_____ _____
(Signature of Witness One) (Address)

Witness Two:
(1) In my presence on _____ (date), _____ (name of declarant) acknowledged the declarant's signature on this document or acknowledged that the declarant directed the person signing this document to sign on the declarant's behalf.
(2) I am at least eighteen years of age.
(3) If I am a health care provider or an employee of a health care provider giving direct care to the declarant, I must initial this box: [ ].

I certify that the information in (1) through (3) is true and correct.

_____ _____
(Signature of Witness Two) (Address)

For more information, contact the North Dakota Catholic Conference, 103 South Third, Suite 10, Bismarck, ND 58501; 701-223-2519, 1-888-419-1237; web: ndcatholic.org; e-mail: ndcatholic@btinet.net

#2

ADVANCE HEALTH CARE PLANNING RESOURCE GUIDE FOR NORTH DAKOTANS

SB2195

MATTERS OF LIFE & DEATH

Several years ago, North Dakotans launched an effort called "Matters of Life & Death" to encourage everyone to talk about our wishes for health care when unable to make or communicate decisions for ourselves. Since that time, the Terri Schiavo story has taught us how important it is for everyone – whatever their age – to make their wishes known in advance.

There were no winners in the long and tragic legal battle involving Terri Schiavo. But her case can impact each of us for the better by spurring us into action to avoid similar scenarios in our own families.

Talking about our wishes for health care if we are unable to do so for ourselves is not just for older people or someone who is near death. Terri Schiavo was a young woman in seemingly good health. And, you may not be near the end of your life when you need someone to speak for you. Critical accidents or severe strokes, as examples, may diminish your ability to make or communicate decisions, even temporarily. Do your wishes in these situations differ from what your wishes might be if you were near death? Will a loved one or a health care agent you appoint be able to express your personal wishes?

Regardless of your age or health status, take the time now *to think about and decide what kind of care you want in the event you are unable to make decisions for yourself. Don't be afraid to talk frankly with your spouse, family, clergy and doctor about your preferences. Remember,* <u>not</u> *talking can result in difficult challenges for those left to make decisions on your behalf.*

Consider naming a health care agent – a person you name and trust who will make decisions for you if you cannot. Take time to fill out a health care directive document and consider all the possibilities or situations in which you may not be able to speak for yourself, even temporarily.

Now is the time to make your wishes known and complete a health care directive. Consider it a gift to yourself as well as your loved ones.

Led by the North Dakota Medical Association, the Matters of Life and Death Project involved a variety of organizations and individuals in North Dakota that made a concerted effort from 1999 to 2003 to improve end-of-life care in North Dakota. The organizations listed in the left column, among others, were involved in this effort.

- AARP
- Association of Hospital Chaplains
- Blue Cross Blue Shield of North Dakota
- Dakota Medical Foundation
- Guardian and Protective Services, Inc.
- Hospice of the Red River Valley
- Mental Health Association of North Dakota
- National Association of Social Workers, ND Chapter
- North Dakota Association for Home Care
- North Dakota Association of County Social Workers
- North Dakota Board of Medical Examiners
- North Dakota Board of Pharmacy
- North Dakota Catholic Conference
- North Dakota Conference of Churches
- North Dakota Department of Human Services
- North Dakota Extension Service
- North Dakota Health Care Review, Inc.
- North Dakota Health Department
- North Dakota Healthcare Association
- North Dakota Hospice Organization
- North Dakota Insurance Department
- North Dakota Long Term Care Association
- North Dakota Long Term Care Ombudsman
- North Dakota Medical Association
- North Dakota Newspaper Association
- North Dakota Nurses Association
- North Dakota Nursing Programs
- North Dakota Office of Attorney General
- North Dakota Pharmacists Association
- North Dakota Right to Life
- State Bar Association of North Dakota
- The Evangelical Lutheran Good Samaritan Society
- ND School of Medicine & Health Sciences

In this guide...

Having the most *important* conversation

Most of us know we *should* talk to a variety of people about our wishes for care when we can't speak for ourselves. It's just that, often, we *don't*. Yet, if we can document and discuss our wishes in advance, a conversation that once seemed scary can actually become comforting.

It really *is* OK to talk about dying. It *has* to be. Use this guide to help you start.

- Hold conversations about your wishes with family, health care providers and others who may be involved in your care.
- Document those wishes, in writing, by preparing a health care directive.

Then, if you are unable to communicate or make decisions in the future, your family, physician and others will know your wishes.

Who needs to talk about it?

You need to start this important conversation if:

- You are an elderly person or you have loved ones who are aging.
- You want to make sure your wishes for health care, at any age, are understood and followed.
- You don't want to burden family members or others with decisions or misunderstandings about your care.
- You want to achieve peace of mind for you and your loved ones.

One Family's Story

For reasons unknown—maybe because her mother was a former nurse—care at the end of life was an issue Anne had talked about with her parents for a long time.

"It just came up really naturally," recalls Anne, "especially as they had friends who were aging or ill. And my parents must have visited about it between them. They were very unified about what they wanted."

After Anne's mother was hospitalized with a brain hemorrhage, Anne realized that, not only had her parents "talked the talk," but that the right paperwork had been done, too. Says Anne: "We had the legal papers—the health care directive—and I knew where they were."

Anne's mother had also spoken with her physician about the kind of care she wanted at the end of life.

"Nobody has ever been clearer with me about her wishes than your mother," the doctor told Anne.

A Gift You Can Give

Talking with other people about your wishes is a true gift you give to those you love!

When you start the conversation—and when you document and discuss your wishes through a health care directive—you can help family, friends, clergy and others who might otherwise be uncertain about what you would want done when you can't speak for yourself. This vital conversation is also a great opportunity to talk about very meaningful issues:

- Your past
- Love and forgiveness
- Relationships
- Hopes and fears
- Spiritual beliefs

Making sure *your wishes* are followed

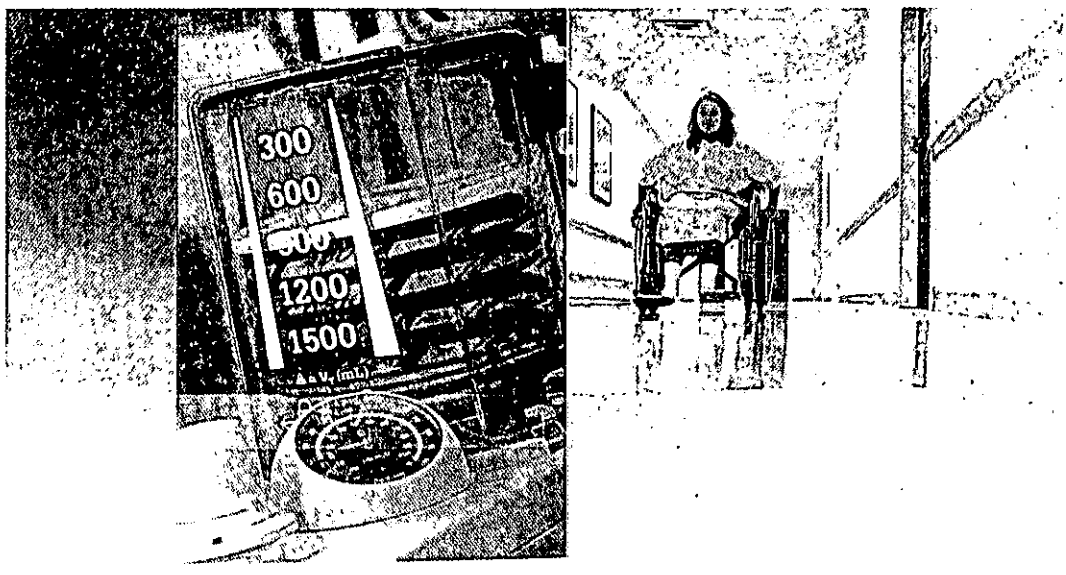
How do you *know* that your wishes for health care will be followed? How can you be certain, for example, that you won't receive unwanted medical treatments that will sustain your life, even if your quality of life is poor? Or, how do you know your life will be prolonged, if you wish, as long as possible?

There is only one way to be as certain as you can that your family, health care providers and others will understand and follow your wishes: *you must put them in writing* using a special form called a "health care directive." (An example of the form is located on pages 15-23 of this resource guide.)

Keep in mind:

- If you do not have a health care directive in place and you become seriously ill or injured, your doctors, hospital staff and loved ones will do the best they can.
- However, without clear direction from you, your loved ones may have to guess what you would want.
- If there is any uncertainty about your wishes, care could be delivered that may not be consistent with your wishes.
- If you want people to know—and follow—your wishes, you should talk with them about your preferences and have a written and signed health care directive in place.

Let this guide help you start the conversations to get that done.



How to *start* the conversation

You need to talk with your loved ones and health care professional about your wishes, so that they understand how you want to be treated if you can't speak for yourself.

Sometimes it is difficult to begin a conversation. But it really *is* OK to do so. How can you start?

- Use this guide and the sample form as a starting point for writing down notes and questions you may have about your options and wishes for care when you can't speak for yourself.
- Talk with those closest to you about your values and preferences for care. This may be an ongoing discussion for a while, and that's OK.
- Talk to your health care professional about medical options and the kinds of treatment you want or do not want.
- Think of other people—including your pastor or attorney—with whom you may also want to talk.
- Document your wishes by completing and signing a health care directive form. (More information and a sample form are found on pages 15-23 of this guide.)

Conversation starters:

- Encourage family members to discuss their plans by talking about your own: "Mom, did you know I have filled out a health care directive?"
- Open conversation by relating to a personal event: "When I was a girl, people never talked about dying, but I think it's important."
- "(Doctor, pastor, etc.), I would like to talk about my options for the end of life and make sure you understand what I want when that time comes."
- Tell a story about someone else's experience with an end-of-life or similar situation and relate that to what you would like your own experience to be.

One Family's Story

While telling family about your wishes may not make all decisions easy, it does provide a roadmap to guide them, a woman named Anne says.

Following a brain hemorrhage, Anne's mother underwent surgery and a variety of treatments. Gradually, though, her condition worsened. Knowing her mother expressly did *not* want to be permanently sustained—particularly after she became unable to speak or take care of herself—Anne and her father were finally able to let go, allowing Anne's mother to die naturally once there was no hope of recovery.

"The gift she gave us was immeasurable," says Anne. "She made it easier for us to make the decision to withdraw futile treatment. Knowing we honored her wishes has made it easier to accept what's happened."

Questions to consider and *issues* to talk about

Are you getting ready to talk? The conversation checklist offers some questions to help you get started. Make sure your specific wishes related to these questions are indicated when you create your health care directive.

Conversation Checklist

Who will you talk to?

Who will be involved in your care and needs to understand your wishes? Think about opening a conversation, or setting up an appointment to do so, with:

- ☐ Family members or loved ones closest to you (list them) _____
- ☐ Your physician or caregiver _____
- ☐ Your pastor or spiritual adviser _____
- ☐ Other people such as your attorney, hospice care provider or funeral home director _____

Where do you want to be when you die? Who do you want around you?

Many North Dakotans want to die at home.

- ☐ Are there services, such as hospice care, that could help you do that?
- ☐ Who do you want near you when you die? What do you want your loved ones to know?

Who do you want to make decisions for you when you can't?

You should name an *agent*, someone you fully trust, who will help to see that your wishes are carried out.

- ☐ Who will be involved in your care?
- ☐ Have you talked to this person about being your agent if you are unable to make or communicate decisions?
- ☐ Does your agent understand your wishes?
- ☐ Does your agent have a copy of your health care directive?

What kinds of medical treatment do you want or not want? What services will you need to be as comfortable as you want to be?

Discuss specific medical options with your health care provider.

- ☐ How do you feel about relying on machines to stay alive?
- ☐ Do you want everything possible to be done to prolong your life?
- ☐ What kind of quality-of-life measures, such as pain management, do you want?
- ☐ How could hospice care help you and your family at the end of life? How can you access those services when that time comes?

Hospice *care* and pain management

Hospice is a form of end-of-life care that focuses on enhancing the quality of life during a person's last days. Hospice services, including medical, emotional, spiritual and grief care, help you stay as comfortable as possible and allow many people to stay in the familiar surroundings of home.

You will want to consider choosing hospice care:

- When you want the focus to be on your comfort and the needs of you and your family.
- For expert help in pain and symptom management.
- When you want your loved ones to have help caring for you while you are dying.

Hospice care can have a positive impact on you and your loved ones.

When you talk about dying

Tell your loved ones, health care provider, spiritual adviser and others:

- Where do you want to die? Do you want to die at home, if possible?
- Are there hospice services that will help your family care for you? How can they access them?
- What kind of help might your loved ones need, if you are dying at home?

Do you have questions about pain and symptom management?

One Family's Story

Dr. Hanson already knew Bill's wishes. Suffering from terminal cancer, 80-year-old Bill had told his physician he wanted no heroic measures.

"When the time comes, just let me go," Bill said.

Near the end of Bill's life, though, his children—concerned about dehydration and nutrition—insisted on continuing IVs and oxygen.

"He was unconscious, and there was no hope he would recover," Dr. Hanson recalls. "I felt we were prolonging his suffering."

Unfortunately, the scenario is familiar to people in medicine.

"Every person should really talk over their wishes with their family as well as their physician," states Dr. Hanson. "And if you have a document on hand, you should show it to your family, too. When you have talked to your family members, it really helps them make decisions in the way you would have wished."

Answers to some of *your* questions

What happens if I don't have a health care directive?

In North Dakota, if you have not appointed a health care agent and you are unable to make or communicate health care decisions, state law will determine who may make health care decisions for you. The law authorizes persons in the following categories, in the order listed, to make decisions:

- Your health care agent, unless a court specifically authorizes a guardian to make decisions for you.
- Your court-appointed guardian or custodian.
- Your spouse.
- Any of your children.
- Your parents.
- Your adult brothers and sisters.
- Your grandparents.
- Your adult grandchildren.
- An adult friend or close relative.

No one in a lower category may provide consent for health care if someone in a higher category has refused to consent to the proposed health care.

Before giving consent, an authorized person must determine that you would have consented to such health care if you were able to do so. If the authorized person is unable to make this determination, he or she may only consent to the proposed health care if he or she feels the health care is in your best interests.

What form can I use?

North Dakota has an optional legal form called a health care directive that you can use to help start conversations and clearly set forth your wishes for the health care you receive if you are unable to make or communicate your decisions. This new form became effective on August 1, 2005. You can use a health care directive to:

- Give instructions about any aspect of your health care.
- Choose a person to make health care decisions for you.
- Give instructions about specific medical treatments you do or do not want.
- Give other instructions, including where you wish to die.
- Make an organ or tissue donation.

There are many other health care directive forms available that meet legal requirements in North Dakota. You should use a form with which you are comfortable and that best reflects your values and preferences. For additional options and resources, see the list of national and state resources on pages 13 and 14.

To be legal in North Dakota, a health care directive must:

- Be in writing.
- Be dated.
- State the name of the person to whom it applies.
- Be executed by a person with the capacity to understand, make and communicate decisions.
- Be signed by the person to whom it applies or by another person authorized to sign on behalf of the person to whom it applies.
- Contain verification of the required signature, either by a notary public or by qualified witnesses.
- Include a health care instruction or a power of attorney for health care, or both.

It is not necessary to have an attorney provide or fill out the form. Nor is it necessary to use a pre-printed form at all. Any written statement that meets the requirements stated above can serve as a legal health care directive. However, you should contact an attorney if you have legal questions regarding advance care planning.

What if I already have a directive that I signed before the new law?

The new law creating the optional health care directive became effective August 1, 2005. If you signed a valid health care directive, living will or durable power of attorney before August 1, 2005, that document remains in effect. You may still wish to review the new optional form and consider whether it would provide a better way for you to express your wishes.

When does a health care directive become effective?

A health care directive is effective when:

1) you have executed a health care directive;
2) your agent has accepted the position as agent in writing; and
3) your doctor has certified, in writing, that you "lack the capacity to make health care decisions."

You lack capacity to make health care decisions when you do not have the ability to understand and appreciate the nature and consequences of a health care decision, including the significant benefits and harms of proposed health care, or reasonable alternatives to that health care, or the ability to communicate a health care decision.

Should I appoint a health care agent?

While it is not required in a health care directive, you may choose another person to make health care decisions for you in the event that you cannot make decisions for yourself. This person is called a health care agent or proxy. Some documents use the term "durable power of attorney for health care" to describe this appointment. In North Dakota, the person you choose as your agent must be 18 years of age or older, and the agent must accept the appointment in writing. In North Dakota, there are certain people you cannot appoint as an agent. These are your health care provider or long-term care services provider, or a non-relative who is employed by your health care provider or long-term care services provider.

The agent has the authority to make the same kinds of decisions about health care that you could make if you were able. This includes the selection and discharge of health care providers and institutions; approval or disapproval of diagnostic tests, surgical procedures, programs of medication and orders not to resuscitate; and directions to provide, withhold or withdraw artificial nutrition and hydration and all other forms of health care. You may limit any of these powers or assign additional ones.

Even if you choose a health care agent, you can still give health care instructions in writing that direct your health care agent in making health care decisions.

Talk beforehand to any person you wish to appoint as your health care agent. Find out if the person is willing to accept the responsibility. Tell them about your wishes and preferences for care. Be sure they are willing and able to follow your wishes.

Can I still make my own health care decisions after I have signed a health care directive?

Yes. You will be able to make your own health care decisions as long as you are capable of doing so. Your agent's authority starts only when your doctor certifies in writing that you do not have the capacity to make health care decisions.

If I am being admitted to or am a patient in a hospital, are there any special requirements?

Yes. The appointment of an agent is not effective if, at the time of execution, you are being admitted to or are a patient in a hospital unless a person designated by the hospital or an attorney licensed to practice law in North Dakota signs a statement that they explained the nature and effect of the appointment to you. This statement is not necessary if you acknowledge in writing that you have read a written explanation of the nature and effect of the appointment.

If I am a resident of a long-term care facility, are there any special requirements?

Yes. If you are a resident of a nursing home or other long-term care facility at the time you sign a health care directive that appoints an agent, that appointment will not be effective unless (1) or (2) occurs:

1) One of the following persons signs a statement affirming that they have explained the nature and effect of the appointment of an agent to you: a member of the clergy, an attorney licensed to practice law in North Dakota, a person designated by the Department of Human Services, or a person designated by the district court in the county where your facility is located; ***OR***

2) You state in writing that you have read an explanation of the nature and effect of the appointment of an agent, or a person designated by the hospital or an attorney licensed to practice law in North Dakota signs a statement affirming that they have explained the nature and effect of the appointment to you.

Will my health care directive be honored?

There are several things you can do to help ensure that your directive is understood and honored. Talk to your loved ones and health care professionals about your wishes and preferences and give them a copy of your directive. Keep your directive up to date. Remember, having a plan and talking about that plan with the people who are important to you ensures that you will have a say in the decisions about your care.

What should I do with my health care directive?

You should keep your original document in a place that is easy to find in the event you should become unable to make or communicate decisions. You should provide a copy of your health care directive to your physician and any other health care providers such as your hospital, nursing facility, hospice or home health agency. In addition, you may want to give copies of your health care directive to other persons, such as close family members and your attorney, if you have one. A copy of a health care directive is generally presumed to be a true and accurate copy of the original.

On page 15,
you will find the North Dakota optional form.

Glossary of commonly used terms

Advance Care Planning: A process of making decisions, in advance, about the care you would want to receive if you are unable to make or communicate decisions for yourself. The process includes conversations with loved ones, health care professionals and others to provide understanding of your values and personal reflections about your wishes and preferences. The process may also include the completion of a health care directive.

Agent: A person appointed to make decisions for someone else, as in a health care directive.

Decision-making Capacity: The ability to understand and appreciate the nature and consequences of one's actions, including the significant benefits and harms of, and reasonable alternatives to, any proposed health care, and the ability to communicate a health care decision.

Durable Power of Attorney for Health Care: One form of health care directive, in which a person appoints an agent to make health care decisions on their behalf, if they are no longer able to make or communicate decisions.

Health Care Decision: This term refers to your decision to consent to, refuse to consent to, withdraw your consent to, or request for any care, treatment, service, or procedure to maintain, diagnose, or treat your physical or mental condition. This includes the selection and discharge of health-care providers and institutions; the approval or disapproval of diagnostic tests, surgical procedures, programs of medication, and orders not to resuscitate; and directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care.

Health Care Directive: A written instrument that includes one or more health care instructions, a durable power of attorney for health care, or both. In North Dakota, state law provides an optional directive form called a "health care directive." Other common terms include "advance directive," a "living will," or "durable power of attorney for health care." These all generally refer to documents in which a person states choices for medical treatment and/or designates who should make treatment choices if the person is unable to make or communicate decisions.

Health Care Instruction: A person's direction concerning a future health care decision, including a written statement of the personal values, preferences, guidelines or directions regarding health care directed to health care professionals, others assisting with health care, family members, an agent, or others.

Living Will: One form of an advance directive in which a person makes a declaration of their wishes regarding health care if they are no longer able to make or communicate decisions.

Patient Self Determination Act: A federal law that requires health care providers to educate their patients and the community on issues related to advance directives. It requires hospitals, nursing facilities, hospices, home health agencies and health maintenance organizations certified by Medicare and Medicaid to furnish written information so that patients have the opportunity to express their wishes regarding the use or refusal of medical care, including life-prolonging treatment, nutrition and hydration. The federal law takes no stand on what decisions persons should make. It does not require persons to execute an advance directive.

Resources and Web site links

North Dakota Resources

ND Senior INFO-LINE
Resource Directory
1-800-451-8693
www.ndseniorinfoline.com

ND Health Care Directive Statutes
www.legis.nd.gov/cencode/t23c065.pdf

ND Medical Association
(701)223-9475
www.ndmed.org

ND Long Term Care Association
(701)222-0660
www.ndltca.org/

ND Healthcare Association
(701)224-9732
www.ndha.org

North Dakota Catholic Conference
1-888-419-1237
www.ndcatholic.org/

Blue Cross Blue Shield of North Dakota
(701)282-1100
www.BCBSND.com

ND Association of Home Care
(701)224-1815
www.aptnd.com/ndahc/

Guardian and Protective Services, Inc.
(701)222-8678; 1-888-570-4277
www.gapsinc.org

ND Right to Life
www.ndrl.org

State Bar Association of ND Lawyer
Referral Program/Volunteer Lawyer
(701)255-1406; 1-800-932-8880
www.sband.org

Legal Assistance of ND
1-800-634-5263
www.legalassist.org

Hospice Programs

Ashley Medical Center Hospice
(701)288-3433

Medcenter One Home Health Hospice, Bismarck
(701)323-8400

St. Alexius Hospice, Bismarck
(701)530-4500
Branch office in Harvey

Presentation Hospice, Carrington
(701)652-7229

Mercy Hospice, Devils Lake
(701)662-2131

Heartland Hospice, Dickinson
(701)456-4378

Hospice of the Red River Valley, Fargo
(701)356-1500
www.hrrv.org
Offices in Fargo, Grand Forks, Lisbon, Mayville and Valley City, North Dakota and Detroit Lakes, Minnesota

Altru Home Services Hospice,
Grand Forks
(701)780-5258
Offices in Park River, Grafton and McVille

Sakakawea Hospice, Hazen
(701)748-2041

Dakota Prairie Helping Hands, Hettinger
(701)567-4975

Jamestown Hospital Hospice
(701)252-1050

Linton Hospital Hospice
(701)254-4511

Trinity Hospitals – Hospice, Minot
(701)857-5083

Heart of America Hospice, Rugby
(701)776-5261

Mercy Hospice, Williston
(701)774-7430

Advance Directives

Aging With Dignity (Five Wishes)
1-888-5-WISHES
www.agingwithdignity.org

Altru Health System (ND and MN Forms), Grand Forks
http://www.altru.org/patientinformation/advancedirectives.htm

Dakota Clinic / Innovis Health, Fargo
www.dakotaclinic.com

Medcenter One Health Systems, Bismarck
http://www.medcenterone.com

MeritCare Health System, Fargo
(ND and MN Forms)
http://www.meritcare.com

St. Alexius / Primecare, Bismarck
http://www.st.alexius.org/

Trinity Health, Minot
http://trinity.minot.org

West River Health Services, Hettinger
http://www.wrhs.com

Minnesota Hospice Organization
www.mnhospice.org

American Health Care Association
www.longtermcareliving.com

National Hospice and Palliative Care Organization
(Caring Connections)
1-800-658-8898
www.nhpco.org

Midwest Bioethics Center
(Caring Conversations)
1-800-344-3829
www.midbio.org

AARP
1-888-687-2277
www.aarp.org/endoflife

American Medical Association
www.ama-assn.org/ama/pub/category/14894.html

American Bar Association
Toolkit for Advance Care Planning
www.abanet.org/aging/toolkit/home.html

American Hospital Association
www.putitinwriting.org

Pain Management

Pain and Policy Study Group
www.medsch.wisc.edu/painpolicy

American Pain Foundation
1-888-615-PAIN(7246)
www.painfoundation.org

HEALTH CARE DIRECTIVE

I, _____, understand this document allows me to do ONE OR ALL of the following:

PART I: Name another person (called the health care agent) to make health care decisions for me if I am unable to make and communicate health care decisions for myself. My health care agent must make health care decisions for me based on the instructions I provide in this document (Part II), if any, the wishes I have made known to him or her, or my agent must act in my best interest if I have not made my health care wishes known.

AND/OR

PART II: Give health care instructions to guide others making health care decisions for me. If I have named a health care agent, these instructions are to be used by the agent. These instructions may also be used by my health care providers, others assisting with my health care and my family, in the event I cannot make and communicate decisions for myself.

AND/OR

PART III: Allows me to make an organ and tissue donation upon my death by signing a document of anatomical gift.

PART I: APPOINTMENT OF HEALTH CARE AGENT

THIS IS WHO I WANT TO MAKE HEALTH CARE DECISIONS FOR ME IF I AM UNABLE TO MAKE AND COMMUNICATE HEALTH CARE DECISIONS FOR MYSELF

(I know I can change my agent or alternate agent at any time and I know I do not have to appoint an agent or an alternate agent.)

NOTE: If you appoint an agent, you should discuss this health care directive with your agent and give your agent a copy. If you do not wish to appoint an agent, you may leave Part I blank and go to Part II and/or Part III. *None of the following may be designated as your agent: your treating health care provider, a nonrelative employee of your treating health care provider, an operator of a long-term care facility, or a nonrelative employee of a long-term care facility.*

When I am unable to make and communicate health care decisions for myself, I trust and appoint _____ to make health care decisions for me.

This person is called my health care agent.

Relationship of my health care agent to me: _____

Telephone number of my health care agent: _____

Address of my health care agent: _____

(OPTIONAL) APPOINTMENT OF ALTERNATE HEALTH CARE AGENT: If my health care agent is not reasonably available, I trust and appoint _____ to be my health care agent instead.

Relationship of my alternate health care agent to me: _____

Telephone number of my alternate health care agent: _____

Address of my alternate health care agent: _____

THIS IS WHAT I WANT MY HEALTH CARE AGENT TO BE ABLE TO DO IF I AM UNABLE TO MAKE AND COMMUNICATE HEALTH CARE DECISIONS FOR MYSELF

(I know I can change these choices.)

My health care agent is automatically given the powers listed below in (A) through (D). My health care agent must follow my health care instructions in this document or any other instructions I have given to my agent. If I have not given health care instructions, then my agent must act in my best interest.

Whenever I am unable to make and communicate health care decisions for myself, my health care agent has the power to:

(A) Make any health care decision for me. This includes the power to give, refuse, or withdraw consent to any care, treatment, service or procedures. This includes deciding whether to stop or not start health care that is keeping me, or might keep me, alive and deciding about mental health treatment.

(B) Choose my health care providers.

(C) Choose where I live and receive care and support when those choices relate to my health care needs.

(D) Review my medical records and have the same rights that I would have to give my medical records to other people.

If I **DO NOT** want my health care agent to have a power listed above in (A) through (D) OR if I want to **LIMIT** any power in (A) through (D), I MUST say that here:

_____

_____

_____

_____

My health care agent is **NOT** automatically given the powers listed below in (1) and (2). If I **WANT** my agent to have any of the powers in (1) and (2), I must **INITIAL** the line in front of the power; then my agent WILL HAVE that power.

____(1) To decide whether to donate any parts of my body, including organs, tissues and eyes, when I die.

____(2) To decide what will happen to my body when I die (burial, cremation).

If I want to say anything more about my health care agent's powers or limits on the powers, I can say it here:

_____

_____

_____

PART II: HEALTH CARE INSTRUCTIONS

NOTE: Complete this Part II if you wish to give health care instructions. If you appointed an agent in Part I, completing this Part II is optional but would be very helpful to your agent. However, if you chose not to appoint an agent in Part I, you **MUST** complete, at a minimum, Part II (B) if you wish to make a valid health care directive.

These are instructions for my health care when I am unable to make and communicate health care decisions for myself. These instructions must be followed (so long as they address my needs).

(A) THESE ARE MY BELIEFS AND VALUES ABOUT MY HEALTH CARE

(I know I can change these choices or leave any of them blank.)

I want you to know these things about me to help you make decisions about my health care.

My goals for my health care:

My fears about my health care:

My spiritual or religious beliefs and traditions:

My beliefs about when life would be no longer worth living:

My thoughts about how my medical condition might affect my family:

(B) THIS IS WHAT I WANT AND DO NOT WANT FOR MY HEALTH CARE

(I know I can change these choices or leave any of them blank.)

Many medical treatments may be used to try to improve my medical condition or to prolong my life. Examples include artificial breathing by a machine connected to a tube in the lungs, artificial feeding or fluids through tubes, attempts to start a stopped heart, surgeries, dialysis, antibiotics and blood transfusions. Most medical treatments can be tried for a while and then stopped, if they do not help.

I have these views about my health care in these situations:

(**Note**: You can discuss general feelings, specific treatments, or leave any of them blank.)

If I had a reasonable chance of recovery and were temporarily unable to make and communicate health care decisions for myself, I would want:

If I were dying and unable to make and communicate health care decisions for myself, I would want:

If I were permanently unconscious and unable to make and communicate health care decisions for myself, I would want:

If I were completely dependent on others for my care and unable to make and communicate health care decisions for myself, I would want:

In all circumstances, my doctors will try to keep me comfortable and reduce my pain.
This is how I feel about pain relief, if it would affect my alertness or if it could shorten my life:

There are other things that I want or do not want for my health care, if possible:

Who I would like to be my doctor:

Where I would like to live to receive health care:

Where I would like to die and other wishes I have about dying:

My wishes about what happens to my body when I die (cremation, burial):

Any other things:

PART III: MAKING AN ANATOMICAL GIFT

I would like to be an organ donor at the time of my death. I have told my family my decision and ask my family to honor my wishes. I wish to donate the following *(initial one statement)*:

[ ] Any needed organs and tissue.

[ ] Only the following organs and tissue: _____

PART IV: MAKING THE DOCUMENT LEGAL

DATE AND SIGNATURE OF PRINCIPAL

(YOU MUST DATE AND SIGN THIS HEALTH CARE DIRECTIVE.)

I revoke any prior health care directive. _____
(you sign here)

I sign my name to this Health Care Directive Form on _____ (date) at _____ (city), _____ (state)

(THIS HEALTH CARE DIRECTIVE WILL NOT BE VALID UNLESS IT IS NOTARIZED OR SIGNED BY TWO QUALIFIED WITNESSES WHO ARE PRESENT WHEN YOU SIGN OR ACKNOWLEDGE YOUR SIGNATURE. IF YOU HAVE ATTACHED ANY ADDITIONAL PAGES TO THIS FORM, YOU MUST DATE AND SIGN EACH OF THE ADDITIONAL PAGES AT THE SAME TIME YOU DATE AND SIGN THIS HEALTH CARE DIRECTIVE.)

NOTARY PUBLIC OR STATEMENT OF WITNESSES

This document must be (1) notarized or (2) witnessed by two qualified adult witnesses. The person notarizing this document may be an employee of a health care or long-term care provider providing your care. At least one witness to the execution of the document must not be a health care or long-term care provider providing you with direct care or an employee of the health care or long-term care provider providing you with direct care. None of the following may be used as a notary or witness:

1. A person you designate as your agent or alternate agent;
2. Your spouse;
3. A person related to you by blood, marriage or adoption;
4. A person entitled to inherit any part of your estate upon your death; or
5. A person who has, at the time of executing this document, any claim against your estate.

OPTION 1: NOTARY PUBLIC

In my presence on _____ (date), _____ (name of declarant) acknowledged the declarant's signature on this document or acknowledged that the declarant directed the person signing this document to sign on the declarant's behalf.

_____
(Signature of Notary Public)

My commission expires _____, 20___.

OPTION 2: TWO WITNESSES

WITNESS ONE:

(1) In my presence on _____ (date), _____ (name of declarant) acknowledged the declarant's signature on this document or acknowledged that the declarant directed the person signing this document to sign on the declarant's behalf.

(2) I am at least eighteen years of age.

(3) If I am a health care provider or an employee of a health care provider giving direct care to the declarant, I must initial this box: [ ].

I certify that the information in (1) through (3) is true and correct.

_____
(Signature of Witness One)

_____

_____
(Address)

WITNESS TWO:

(1) In my presence on _____ (date), _____ (name of declarant) acknowledged the declarant's signature on this document or acknowledged that the declarant directed the person signing this document to sign on the declarant's behalf.

(2) I am at least eighteen years of age.

(3) If I am a health care provider or an employee of a health care provider giving direct care to the declarant, I must initial this box: [ ].

I certify that the information in (1) through (3) is true and correct.

_____
(Signature of Witness Two)

_____

_____
(Address)

ACCEPTANCE OF APPOINTMENT OF HEALTH CARE AGENT

I accept this appointment and agree to serve as agent for health care decisions. I understand I have a duty to act consistently with the desires of the principal as expressed in this appointment. I understand that this document gives me authority over health care decisions for the principal only if the principal becomes incapacitated.

I understand that I must act in good faith in exercising my authority under this power of attorney. I understand that the principal may revoke this appointment at any time in any manner.

If I choose to withdraw during the time the principal is competent, I must notify the principal of my decision. If I choose to withdraw when the principal is not able to make health care decisions, I must notify the principal's physician.

_____

(Signature of agent/date)

_____

(Signature of alternate agent/date)

PRINCIPAL'S STATEMENT

(Only necessary if you are a resident of a long-term care facility or are a hospital patient or person being admitted to a hospital. The principal's statement is an alternative to the explanation required on page 23.)

I have read a written explanation of the nature and effect of an appointment of a health care agent that is attached to my health care directive.

Dated this day of _____, 20___ .

_____

(you sign here)

STATEMENT AFFIRMING EXPLANATION OF DOCUMENT TO RESIDENT OF LONG-TERM CARE FACILITY

(Only necessary if you are a resident of a long-term care facility and Part I is completed appointing an agent. This statement does not need to be completed if you have read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement on page 22.)

I have explained the nature and effect of this health care directive to _____
(Name of principal)

who signed this document and who is a resident of _____
(Name and city of facility)

I am *(check one of the following)*:

[ ] A recognized member of the clergy.

[ ] An attorney licensed to practice in North Dakota.

[ ] A person designated by the district court for the county in which the above-named facility is located.

[ ] A person designated by the North Dakota Department of Human Services.

Dated on _____, 20___. _____
(Signature)

STATEMENT AFFIRMING EXPLANATION OF DOCUMENT TO HOSPITAL PATIENT OR PERSON BEING ADMITTED TO HOSPITAL

(Only necessary if you are a patient in a hospital or are being admitted to a hospital and Part I is completed appointing an agent. This statement does not need to be completed if you have read a written explanation of the nature and effect of an appointment of a health care agent and completed the Principal's Statement on page 22.)

I have explained the nature and effect of this health care directive to _____
(Name of principal)

who signed this document and who is a patient or is being admitted as a patient of

_____
(Name and city of hospital)

I am *(check one of the following)*:

[ ] An attorney licensed to practice in North Dakota.

[ ] A person designated by the hospital to explain the health care directive.

Dated on _____, 20___. _____
(Signature)

ERRATA

There are changes in North Dakota law made by the 2007 North Dakota Legislative Assembly that impact this printing of the *Advance Health Care Planning Resource Guide for North Dakotans*.

The first change is on page 9. The following language should be added to the answer to the question: When does a health care directive become effective?

> "As a result of legislation enacted by the 2007 ND Legislative Assembly, you may choose to authorize your health care agent to make health care decisions for you even if you still have the capacity to make those decisions (rather than only when you have become incapacitated). Under this option, the health care directive is effective under any conditions you may impose. You may also revoke this authorization as you would any other health care directive."

The second change is on page 10. The answer to the last question on that page should be as follows:

> "If I am being admitted to or am a patient in a hospital, are there any special requirements?
>
> "Previous law required that a person being admitted to a hospital, or a hospital patient, who appoints a health care agent to receive an explanation of the nature and effect of the appointment in order that the appointment be effective. A special form needed to be completed. However, the requirement was removed by the 2007 ND Legislative Assembly effective August 1, 2007."

The third change is to the first question on page 11, with the following new answer:

> "If I am a resident of a long-term care facility, are there any special requirements?
>
> "No. Previous law required that a resident of a nursing home or other long-term care facility who appoints a health care agent to receive an explanation of the nature and effect of the appointment in order that the appointment be effective. A special form needed to be completed. However, the requirement was removed by the 2007 ND Legislative Assembly effective August 1, 2007."

The fourth change is the removal of the following portions of the optional form:

> Remove the Principal's Statement on the bottom half of page 22.
> Remove the entire page 23.

#1

TESTIMONY IN SUPPORT OF SB 2195

House Human Services Committee
March 17, 2009

Chairman Weisz and Members of the Committee:

Happy St. Patrick's Day! My name is Patrick Ward and I represent LifeSource, the non-profit organ and tissue donation procurement organization for the upper great plains states including North Dakota.

The North Dakota legislature adopted the revised UAGA in 2007 with the goal of further advancing organ and tissue donation in the State of North Dakota. In passing this legislation this legislature respected the importance of uniformity and consistency in the donation process across state lines. You passed the original Uniform Law language last session with only minimal amendments.

In the midst of the 2007 Legislative Session the NCCUSL Standby Committee for the Uniform Anatomical Gift Act recommended an amendment to Section 21 of the Act. North Dakota was unable to include this amendment as the legislation had already been passed by the legislature. SB 2195 simply amends the Uniform Anatomical Gift Act in keeping with the amendment put forward by the National Conference of Commissioners on Uniform State Laws (NCCUSL).

The national transplant waiting list holds the names of more than 100,000 men, women and children who are waiting for a life-saving organ transplant; 2,745 of whom are listed at transplant centers in the LifeSource region of Minnesota, North Dakota, and South Dakota. There are numerous success stories. One of these is my own uncle Fabian, a dairy farmer in northern Minnesota. He is still alive today more than 20 years after having received a donated heart. I just saw him again over crossover. Unfortunately, the flip side is that each day 18 people in the United States are removed from the transplant waiting list by death.

North Dakota has a history of strong leadership in donation. More than 300,000 North Dakotans have registered their intention to donate organs and tissue upon their death, representing 62% of licensed drivers. People of all ages can be donors. In 2008 alone, more than 19,000 people in the state made this life-saving decision. This increase illustrates the care and generosity of North Dakotans and their willingness to help others. Clearly the process for designating oneself a donor has been effective. However, sometimes donors or families need to understand that withdrawing mechanical support can cause vital organs to die and no longer be viable for transplantation. This bill would help donors and their families understand the problem and make clear decisions on when to withhold and when to continue mechanical support.

LifeSource supports SB 2195 to amend the Uniform Anatomical Gift Act as it provides further direction on how to honor and fulfill both an individual's end-life

wishes as expressed in an advanced health care directive and simultaneously fulfill opportunities for saving lives through donation. Passage of this amendment will also ensure continued consistency and uniformity in donation legislation across state lines.

The existing language was written with the goal of eliminating any potential conflict between end-of-life wishes and opportunities for organ and tissue donation. Section 23-06.6-20 provides guidance on how to resolve this situation by requiring involvement of the physician, donor or their family, and the procurement organization in the process.

I would also like to introduce Judge Gail Hagerty who has been very involved with the National Conference of Commissioners on Uniform State Laws in drafting this legislation. Judge Hagerty is also a member of the LifeSource Board of Directors. She is available to answer any questions if I cannot.

We urge you give SB 2195 a unanimous do pass recommendation. Judge Hagerty and I will try to answer any of your questions about this bill. Thank you.

P:\PWARD\Legislative 2009\TESTIMONY IN SUPPORT OF SB 2195.doc

NORTH DAKOTA MEDICAL ASSOCIATION

1622 East Interstate Avenue
Post Office Box 1198
Bismarck, North Dakota
58502-1198

(701) 223-9475
Fax (701) 223-9476

Robert A. Thompson, MD
Grand Forks
President

Kimberly T. Krohn, MD
Minot
Vice President
Council Chair

A. Michael Booth, MD
Bismarck
Secretary-Treasurer

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Bismarck
AMA Delegate

Robert W. Beattie, MD
Grand Forks
AMA Alternate Delegate

Shari L. Orser, MD
Bismarck
Immediate Past President

Bruce Levi
Executive Director

Dean Haas
General Counsel

Leann Tschider
Director of Membership
Office Manager

Annette Weigel
Administrative Assistant

Testimony in Support of Senate Bill No. 2195
House Human Services Committee
March 17, 2009

Chairman Weisz and Committee Members, I'm Bruce Levi and I serve as the Executive Director of the North Dakota Medical Association. The North Dakota Medical Association is the professional membership organization for North Dakota physicians, residents and medical students.

SB No. 2195 addresses the need for an appropriate balance between respecting wishes about end-of-life care and organ donation. The North Dakota Medical Association supports both organ donation and quality end-of-life care. They are not mutually exclusive considerations in most cases. This bill recognizes that in appropriate cases briefly continuing life support to enable organ donation may allow an important end-of-goal of the patient to be achieved.

Late last legislative session, the amendment to the Revised (2006) Uniform Anatomical Gift Act made on March 27, 2007, by the National Conference of Commissioners on Uniform State Laws was raised and it was agreed to defer the issue until this legislative session. A criticism of Section 21 of the Revised (2006) Uniform Anatomical Gift Act, now codified at NDCC Section 23-06.6-20, was that the 2006 Act allowed donation to supersede other end-of-life care considerations if there was a conflict between an individual's anatomical gift and the individual's health care directive, unless the health care directive expressly stated otherwise.

The amendment to Section 21 of the 2006 UAGA now recognizes that organ donation consideration is one part of end-of-life care and states clearly that organ donation should not interfere with quality end-of-life care. The conflict resolution approach embraced in SB No. 2195 is a reasonable approach, in our view, that accommodates both organ donation and end-of-life care considerations.

Many view our current law, in aiming to prevent advance directives from precluding organ donation, as giving organ donation *priority* over a person's advance directive regarding their end-of-life care and physician orders for life-sustaining treatment ["If a prospective donor has a declaration or advance health care directive, measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor, unless the declaration or advance health care directive expressly provides to the contrary." NDCC Section 23-06.6-20(2)].

SB 2195 would replace Section 23-06.6-20(2) with the following conflict resolution process:

> If a prospective donor has a declaration or advance health care directive and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of a part for transplantation or therapy, the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, an agent acting under the prospective donor's declaration or directive or, if none or the agent is not reasonably available, another person authorized by law other than this chapter to make health care decisions on behalf of the prospective donor shall act for the donor to resolve the conflict. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under section 23-06.6-09. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures *is not contraindicated by appropriate end-of-life care.*

In our view, the new language reflected in SB 2195 as adopted by the National Conference of Commissioners on Uniform State Laws greatly improves the North Dakota version of the Revised Uniform Anatomical Gift Act, ensuring that dying patients' wishes about their end-of-life care are protected. As stated in the attached article, DeVita, Caplan, *Caring for Organs or for Patients? Ethical Concerns about the Uniform Anatomical Gift Act (2006),* Annals of Internal Medicine, December 2007, this revised language recognizes a long term and important ethical precept: "Care of dying patients takes precedence over organs. Another laudable goal must be promoted as well: Organ donation is an important part of end-of-life care."

As has been the case previously in our state with both organ donation and advance care planning legislation, this bill raises the professional imperative that physicians and hospitals fulfill their responsibilities to educate patients on our state's new health care directive law and anatomical gift law and encourage patients to expressly document their preferences about the use of life support systems for organ donation at the end-of-life.

Our recently revised (2005 and 2007) health care directive law facilitates the likelihood that a North Dakota patient will expressly address the use of life support systems for organ donation by including a specific provision relating to anatomical gifts in the statutory health care directive form (NDCC 23-06.5-05.1(5) and 23-06.5-17), thereby encouraging consideration of any potential conflict.

Thank you for the opportunity to testify on behalf of the North Dakota Medical Association. We urge a "Do Pass" on SB No. 2195.

North Dakota Catholic Conference

Representing the Diocese of Fargo and the Diocese of Bismarck

Christopher T. Dodson
Executive Director and
General Counsel

To: House Human Services Committee
From: Christopher T. Dodson, Executive Director
Subject: Senate Bill 2195
Date: March 17, 2009

The North Dakota Catholic Conference opposes Senate Bill 2195 in its current form, but believes the bill could be remedied with amendments that further the goal of encouraging anatomical gifts..

The Catholic Church strongly encourages organ donation. Organ donation after death is a noble and meritorious act and an expression of solidarity. The health care directive published by the North Dakota Catholic Conference has a section whereby people can state their request to make an anatomical gift. Last year, the conference sponsored a day-long workshop on organ donation and transplantation. So it is not from an attempt to discourage anatomical gifts that we raise concerns about SB 2195. Indeed, is it with the hope of *not* discouraging organ donation that we raise these issues.

In order for the public to accept and participate in organ donation -- as well as to be ethically acceptable -- donations must be made with informed consent and in a manner consistent with the donor's wishes. This is the case with all health care procedures. For this reason North Dakota health care directive statute requires that decisions be made "in accordance with the agent's knowledge of the principal's wishes and religious or moral beliefs, as stated orally, or as contained in the principal's health care directive."

This legislative body has determined that whenever a person with a health care directive cannot speak for himself or herself, the person's health care directive prevails. Senate Bill 2195 would change this policy by placing potential anatomical gifts at the same level as a health care directive. The directive would no longer prevail. Instead, it forces the parties to resolve conflicts between the health care directive and the potential donation. In fact, lines 8 - 11 on page 2 of the bill go further, allowing procedures to be taken pending resolution of the

103 S. 3rd St., Suite 10 • Bismarck, ND 58501
(701) 223-2519 • 1-888-419-1237 • FAX # (701) 223-6075
http://ndcatholic.org • ndcatholic@btinet.net

conflict, *even if they contradict the health care directive*. This, in effect, gives priority to the potential anatomical gift.

This change has real consequences. Some measures used to enhance medical suitability of organs and tissue for transplantation raise serious ethical questions that have not been, and may not be, resolved. Like all health care procedures, these questions should be resolved in favor of the person's health care directive.

Failure to respect and give priority to health care directives could ultimately undermine the Uniform Anatomical Gift Act's purpose of fostering anatomical gift donation. Health care directives are the primary means by which a person indicates their health care wishes and the religious and moral beliefs that should guide and limit health care decisions. This principle guided us during years of work to improve and encourage the use of health care directives.

In the many workshops I have given on health care directives in North Dakota, one of the most commonly expressed reservations about executing a directive is concern that a physician's wishes or interpretation of directive would prevail over the beliefs and principles set out in the directive. Similarly, a common concern about expressed about organ donation is that it will be done in a manner contrary to a person's religious beliefs. In both cases, people want assurance that that under the law, the health care directive would prevail.

By elevating procedures to facilitate organ donation to the same level - or to a greater level - than health care directives, Senate Bill 2195 in its current form risks removing the sense of security people need before they will execute health care directives or make organ donations. Thus, in addition, to creating ethical problems, SB 2195, if not amended, threatens the work so many have done to encourage both organ donation and health care directives.

We think, however, that Senate Bill 2195 can be remedied by incorporating the standard that already applies to every other type of health care decision in North Dakota -- that decisions be made in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs, as stated orally, or as contained in the health care directive.

NDLA, S HMS

From: Lee, Judy E.
Sent: Tuesday, March 24, 2009 8:17 AM
To: NDLA, S HMS
Subject: FW: SB 2195 UAGA Revisions -and need to fix House amendments in conference committee
Attachments: Senate Bill 2195.docx

Mary –
Please tuck this in the record for 2195 for future reference.

Senator Judy Lee
1822 Brentwood Court
West Fargo, ND 58078
home phone: 701-282-6512
e-mail: jlee@nd.gov

From: Patrick Ward [mailto:pward@zkslaw.com]
Sent: Monday, March 23, 2009 11:02 AM
To: Lee, Judy E.; Dever, Dick D.
Cc: Bruce Levi; North Dakota Catholic Conference; Hagerty, Gail
Subject: FW: SB 2195 UAGA Revisions -and need to fix House amendments in conference committee

Judy:

I am attaching some points explaining why LifeSource does not agree with the House Amendments and would like a conference committee on Senate Bill 2195 with House Amendments to try and forge a compromise on this bill. Attached is a comparison of the original bill and the house version.

As you know, the original bill was a UAGA amendment which has been adopted in 18 states.

Our proposed language to compromise the two positions is in red. I am having Kara Johnson put the amendments in proper form and we will get those to you as soon as they are done. We will also share these with Bruce Levy and Chris Dodson as we go along.

I am hoping there is a middle ground somewhere that accomplishes everybody's wishes but does not stray too far from the model act.

Patrick Ward
Zuger Kirmis & Smith
PO Box 1695
Bismarck ND 58502
701-223-2711
FAX 701-223-9619

From: Susan Mau Larson [mailto:smlarson@life-source.org]
Sent: Monday, March 23, 2009 9:04 AM
To: Patrick Ward
Subject: RE: UAGA Revisions - a Heads Up

Pat,

Here you go. I must have attached the wrong document.

[redacted]an Mau Larson
[redacted]rector, Public Affairs
651-603-7852
612-968-2940 (cell)

Save lives... register to be an organ and tissue donor.

www.donatelifemn.org

From: Patrick Ward [mailto:pward@zkslaw.com]
Sent: Monday, March 23, 2009 8:46 AM
To: Susan Mau Larson
Subject: RE: UAGA Revisions - a Heads Up

Susan:

Can you please resend the attachement. All I got was the bill itself.

-----Original Message-----
From: Susan Mau Larson [mailto:smlarson@life-source.org]
Sent: Sun 3/22/2009 7:31 PM
To: Patrick Ward
[redacted]ject: RE: UAGA Revisions - a Heads Up

Pat,

I agree that we need to try to find a middle ground. I reviewed the two versions closely. Attached is a document with a line-by-line comparison of the two, a summary of concerns with the current language, and then a proposed compromise. The compromise language I included is based off the NDCC language with additions in red.

Please let me know if you think this is something we could bring forward. I will also send this to NCCUSL to look at to make sure I have not missed anything.

I am in the office tomorrow and we can discuss it. Thank you for all of your help. I hope you are doing something fun on Thursday and Friday.

Susan Mau Larson
Director, Public Affairs
651-603-7852
612-968-2940 (cell)

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www.donatelifemn.org<http://www.donatelifemn.org>

From: Patrick Ward [mailto:pward@zkslaw.com]
Sent: Friday, March 20, 2009 2:36 PM
To: Susan Mau Larson
Cc: Kara Johnson
[redacted]ct: RE: UAGA Revisions - a Heads Up

Susan:

I can talk to Judy Lee on Monday. I am not sure I see a middle ground. Best solution might be to work off their amendments somehow. Let me know. I am going to have Kara help me with his because I am gone next Thursday and Friday.

[redacted]trick Ward
[redacted]er Kirmis & Smith
[redacted] Box 1695
Bismarck ND 58502
701-223-2711
FAX 701-223-9619

From: Susan Mau Larson [mailto:smlarson@life-source.org]
Sent: Thursday, March 19, 2009 4:04 PM
To: Patrick Ward
Subject: FW: UAGA Revisions - a Heads Up
From Conniee Ring

Susan Mau Larson
Director, Public Affairs
651-603-7852
612-968-2940 (cell)

Save lives... register to be an organ and tissue donor.

www.donatelifemn.org<http://www.donatelifemn.org>

From: Ring, Carlyle [mailto:ccring@ober.com]
Sent: Thursday, March 19, 2009 8:57 AM
To: Susan Mau Larson
[redacted]Nicole Julal; Kurtz, Sheldon F
[redacted]ect: RE: UAGA Revisions - a Heads Up

SUSAN:

In Maryland, I had extended discussions with the Maryland Catholic Conference on Section 21 and we agreed upon language that is perhaps related to the concern in North Dakota. However, keep in mind that the Maryland Bill is not going to be considered until next year for various reasons. The focus in Maryland was not on the last sentence of Section 21 (b), as the Catholic Conference was comfortable that the last sentence authorized the end of life (EOL) physician to withhold or withdraw the organ sustaining measures (ventilation) if required by appropriate end of life care. Their concern instead focused on the circumstance where the donor or more likely his or her health care agent, could not or would not act to resolve the conflict, then do the measures continue indefinitely? In most cases, if the patient is near death, death is going to happen and forecloses any donation. However, in the event of indecision, Shelly (the Reporter) and I agreed to the insertion immediately prior to the penultimate sentence the following: "If the conflict is not resolved expeditiously, the direction of the declaration or advance directive shall apply and control." This sentence satisfied the Maryland Catholic Conference and they agreed to support the Bill with this change.

I do not recall any enactment that has modified the last sentence of subsection (b) [Nicole-- do you recall any?]

But I have had some discussions over the wording of the last sentence (but no request for a change in the wording) because it is cast in the negative instead of the positive. Perhaps it would be better understood and cause less concern if it were reworded to read:

"Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn unless the end of life physcian
determines that appropriate end of life care requires that they be withheld or withdrawn."

I would first test whether the wording in the first paragraph above that was acceptable to the Maryland Catholic Conference is acceptable to the North Dakota Catholic Conference. If not, maybe you might that the wording I suggested in the paragraph above.

[redacted]y is unavailable on the moment but you will note that a copy of this is being sent to him. If he has further thoughts I will pass them on to you.

I would be glad to chat further.

CONNIE RING
[redacted]2-326-5049
[redacted]ir of NCCUSL Drafting Committee for RUAGA

From: Susan Mau Larson [mailto:smlarson@life-source.org]
Sent: Wednesday, March 18, 2009 1:39 PM
To: Ring, Carlyle
Cc: Nicole Julal
Subject: FW: UAGA Revisions - a Heads Up
Update from ND.

Susan Mau Larson
Director, Public Affairs
651-603-7852
612-968-2940 (cell)

Save lives... register to be an organ and tissue donor.

www.donatelifemn.org<http://www.donatelifemn.org>

From: Patrick Ward [mailto:pward@zkslaw.com]
Sent: Wednesday, March 18, 2009 10:49 AM
To: Susan Mau Larson
Subject: FW: UAGA Revisions - a Heads Up

[redacted]ick Ward
Zuger Kirmis & Smith
PO Box 1695
Bismarck ND 58502
701-223-2711
FAX 701-223-9619

From: North Dakota Catholic Conference [mailto:ndcatholic@csicable.net]
Sent: Wednesday, March 18, 2009 8:22 AM
To: Patrick Ward
Cc: Bruce Levi
Subject: Re: UAGA Revisions - a Heads Up
Pat:

Perhaps I am missing something, but I don't see how that proposed change would make the bill much different than the existing law. It certainly does not address any of the three problems raised:

(1) the problem of giving greater weight in the law to procedures related to procurement than we give to other procedures;
(2) the problem of not applying the same standard - or any standard - for resolving conflicts that we apply to other procedures and questions; and
(3) the problem of not distinguishing between measures that temporarily sustain life and measures that have no indicated purpose other than making an organ suitable. From the view of most ethicists, such a distinction should not be made, but from a real world perspective, there is a difference.

[redacted]topher Dodson
Executive Director

General Counsel
North Dakota Catholic Conference
103 South Third Street, Suite 10
Bismarck, ND 58501
[redacted]-223-2519
[redacted]://ndcatholic.org

On Mar 17, 2009, at 4:36 PM, Patrick Ward wrote:

Chris, Robin and Bruce:

I am thinking this language below in red might work. I am not sure how else to say it without wiping out the meaning of the preceding language.

I did find out that 18 states have the new language, 10 are the same as ND now, 3 have significant variations and 3 omitted this section.
Our suggested change to the last line in the bill is in red below. This starts on line 8 of page 2. Before resolution of the conflict, measures necessary to ensure the
medical suitability of the part may not be withheld or withdrawn from the
prospective donor if withholding or withdrawing the measures is not contraindicated
by appropriate end-of-life care unless the declaration or advance health care directive expressly provides to the contrary.

Let me know what you think.

Patrick Ward
Zuger Kirmis & Smith
PO Box 1695
Bismarck ND 58502
701-223-2711
FAX 701-223-9619

[redacted]

From: North Dakota Catholic Conference [mailto:ndcatholic@csicable.net]
Sent: Tuesday, March 17, 2009 2:49 PM
To: Patrick Ward
Cc: Bruce Levi
Subject: UAGA Revisions - a Heads Up
Pat:

Following our earlier conversations today, Rep. Weisz tracked me down and asked if I had a suggested amendments for the bill. I mentioned that we had just talked about limiting the last sentence to life sustaining measures and that although that would not resolve all our concerns, I thought we could work with it. He, however, did not like that idea and wanted to see amendments that would make decisions subject to the health care directive. Since Bruce and I had worked on something along those lines earlier, I said I would get it to him.

I just wanted you to know that I was not doing a end-run around you.

Christopher Dodson
Executive Director
General Counsel
North Dakota Catholic Conference
103 South Third Street, Suite 10
Bismarck, ND 58501
701-223-2519
http://ndcatholic.org

[redacted]

March 25, 2009

North Dakota Senate Bill 2195

Original amendment	House version
If a prospective donor has a declaration or advance health care directive, and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of an organ a part for transplantation or therapy may not be withheld or withdrawn from the prospective donor, unless the declaration or advance health care directive expressly provides to the contrary, the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, *an agent acting under the prospective donor's declaration or directive or, if none or the agent is not reasonably available, another person authorized by law other than this chapter to make health care decisions on behalf of the prospective donor shall act for the donor to resolve the conflict. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under section 23-06.6-09. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn from the prospective donor if withholding or withdrawing the measures is not contraindicated by appropriate end-of-life care.*	If a prospective donor has a declaration or advance health care directive, and the terms of the declaration or directive and the express or implied terms of a potential anatomical gift are in conflict with regard to the administration of measures necessary to ensure the medical suitability of an organ a part for transplantation or therapy may not be withheld or withdrawn from the prospective donor, unless the declaration or advance health care directive expressly provides to the contrary, the prospective donor's attending physician and prospective donor shall confer to resolve the conflict. If the prospective donor is incapable of resolving the conflict, *the attending physician, as expeditiously as possible, shall confer with an agent acting under the prospective donor's declaration or directive or, if none or the agent is not reasonably available, another person authorized by law other than this chapter to make health care decisions on behalf of the prospective donor. In resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs, as stated orally, or as contained in the declaration or advance health care directive.*

Concerns with current language

- The language stating the conflict must be resolved as expeditiously as possible has been removed. It would seem to be in the best interest of the patient and their family to resolve any concerns quickly.
- The language stating that information may be obtained from the appropriate procurement organization has been eliminated. A procurement organization understands the potential for donation, the impact of the donation and the donation process and this information is relevant to resolving the conflict.

- The last line ensures that measures necessary to ensure donation may not be withheld or withdrawn. In most cases the measures necessary are already in place so this is primarily related to withdrawing them. If this line is absent and measures are withdrawn prior to resolution of the conflict then donation cannot proceed. If this resolution were to proceed with donation this would truly be a second loss for the potential donor and their family.
- The new language notes that the agents' decision must be in accordance with a prospective donor's wishes. Certainly if a prospective donor had documented their wishes to donate those would be considered in all situations. That is an end-of-life wish that we strive to honor.
- If a person had not documented their wishes to donate it is unclear how their religious and moral beliefs could be verified and understood. Is this something the procurement organization would be obligated to verify to ensure proper authorization for donation was obtained?

Suggested compromise language

the attending physician, as expeditiously as possible, shall confer with an agent acting under the prospective donor's declaration or directive or, if none or the agent is not reasonably available, another person authorized by law other than this chapter to make health care decisions on behalf of the prospective donor. The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under section 23-06.6-09. In resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's known wishes and beliefs, as stated orally, or as contained in the declaration or advance health care directive. Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn unless the end of life physician determines that appropriate end of life care requires that they be withheld or withdrawn.

#1

April 15, 2009
Conference Committee
Patrick J. Ward

LIFESOURCE PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL 2195

That the Senate accede to the House amendments as printed on page 1010 and adopted on page 1021 of the House Journal and that Engrossed Senate Bill No. 2195 be further amended as follows:

Page 2, line 4, after "donor." insert "The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under section 23-06.6-09."

Page 2, line 8, after "directive." insert "Before resolution of the conflict, measures necessary to ensure the medical suitability of the part may not be withheld or withdrawn unless the administration or continued administration of such measures would constitute inappropriate care."

Renumber accordingly

Christopher Dodson

#2

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL 2195

That the Senate accede to the House amendments as printed on page 1010 and adopted on page 1021 of the House Journal and that Engrossed Senate Bill No. 2195 be further amended as follows:

Page 2, line 4, after "donor." insert "The conflict must be resolved as expeditiously as possible. Information relevant to the resolution of the conflict may be obtained from the appropriate procurement organization and any other person authorized to make an anatomical gift for the prospective donor under section 23-06.6-09."

Page 2, line 8, after "directive." insert "Before resolution of the conflict, life-prolonging measures necessary to ensure the medical suitability of the part may be provided unless the administration or continued administration of such measures would constitute inappropriate end-of-life care."

Renumber accordingly

#3

ZUGER KIRMIS & SMITH

COUNSELORS AND ATTORNEYS AT LAW

Lyle W. Kirmis
Lance D. Schreiner, P.C.
James S. Hill, P.C. **^
Patrick J. Ward*++^
Rebecca S. Thiem, P.C.**
Jerry W. Evenson, P.C.^
Lawrence A. Dopson
Lawrence E. King, P.C.**^^
Tracy Vigness Kolb, P.C.
Shawnda R. Ereth**+
Constance N. Hofland**
Paul R. Sanderson, P.C.
Kara J. Johnson
Carey A. Goetz**~

316 North Fifth Street
Provident Building
P.O. Box 1695
Bismarck, ND 58502-1695
(701) 223-2711
fax (701) 223-7387
www.zkslaw.com
email: zkslaw@zkslaw.com

John A. Zuger
1940-2006
Thomas O. Smith
1944-2001

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^Certified Civil Trial Specialist
National Board of Trial Advocacy

April 16, 2009

Senator Robert Erbele
Senator Judy Lee
Senator Richard Marcellais
Representative Robin Weisz
Representative Todd Porter
Representative Tork Kilichowski

I am writing this letter in follow up to the discussions had at the SB 2195 conference committee meeting on April 15, 2009. I believe there was a consensus to adopt the two additional sentences proposed by LifeSource through agreement with the North Dakota Catholic Conference and the North Dakota Medical Association after discussion.

The one remaining question was the issue whether the phrase "measures necessary to insure the medical suitability of the part" in the second sentence to be inserted should contain some modifier such as life-prolonging, life-sustaining, or sustaining.

I have discussed this issue with my client at LifeSource and we would have no problem with the word sustaining without the word life being used in that particular location.

Our concern with using a phrase such as life-prolonging or life-sustaining is that in many of these situations the individual is already legally dead either by way of cardiac or brain stem death. However, there is still a window of opportunity to salvage organs or parts that can be used to prolong and sustain the life of another individual.

As I indicated, this bill simply provides for keeping the organ or part viable for a short period of time while the donor's intention with respect to donation is determined. This period of time is almost always less than 24 hours.

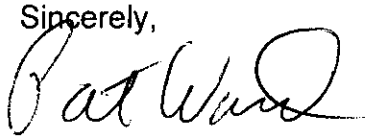
The burning question that we all left the conference committee with is whether or not a healthcare directive survives the death of the individual. After reviewing the healthcare directive statute, discussing this with my client, some of my partners and others, it is my opinion that the agent appointed in the healthcare directive no longer has power because the healthcare directive expires when the individual expires. However, the intention of organ donation survives the "brain" or "cardiac" death of the individual.

I will assure you that whether or not this bill is adopted, I will make it a point to educate members of the North Dakota Bar Association who prepare wills and healthcare directives for people to the fact that they should discuss specifically the issue of organ donation with those individuals and the particular situation we are presented with in this bill in order to avoid any uncertainty as to donor intent in such situations.

However, I did want you to know that from everything I can gather through my research, the agency provided or created in a healthcare directive, like the power of attorney in a durable power of attorney, expires when the individual granting the agency or power legally passes away.

I hope this is helpful.

Sincerely,



Patrick J. Ward

C:\SB 2195.doc

#4

LifeSource
Organ & Tissue Donation

April 16, 2009

TO: Pat Ward

FROM: Susan Mau Larson

RE: LifeSource donors

In 2008 LifeSource had the honor of working with 147 organ donors and their families. The gifts from these generous individuals provided a second chance at life for 475 grateful recipients and their families.

The option of organ donation is most often offered after brain death is declared. Brain death occurs when blood no longer flows to the brain, all brain functions cease and the brain dies. A person who is brain dead cannot breathe, think or feel. The time an individual is declared brain dead by a physician is the legal time of his or her death. The patient is kept on a ventilator to keep the heart beating and providing blood and oxygen to their organs. In 2008, 128 organ donors in the LifeSource region donated after brain death.

There are times when a family will make a decision to withdraw treatment on behalf of a loved one who has suffered a devastating brain injury, but is not brain dead. Following the discontinuation of treatment, there are infrequent cases in which organ donation is an option. This process is called Donation after Cardiac Death. Families are provided the opportunity for donation in these cases only after they have independently made the decision to withdraw treatment. Following authorization for donation, and prior to the withdrawal of treatment, organ function is evaluated and the gifts are allocated to individuals waiting for a life-saving organ. The hospital care team withdraws treatment and following the patient's death, the organs are recovered for transplant. In 2008, LifeSource worked with the families of 19 individuals in this situation.

In Donation after Cardiac Death cases heparin is administered at the time of withdrawal of support in accordance with current standards of care and hospital policy. The administration of heparin ensures the best possible outcome for organ recipients. In donation after cardiac death cases the family is very involved in all aspects including the decision to administer heparin.

LifeSource is humbled to work with the amazing donors and their families who at a time of grief reach out to help others in need. In all donation cases LifeSource provides compassionate and sensitive care to the families, both at the time of donation and in the months and years to follow.

CENTRAL OFFICE 2550 University Avenue West, Suite 315 South, St. Paul, Minnesota 55114-1904 / Phone: 651-603-7800
Fax: 651-603-7801 / **Donor Referral:** 1-800-24-SHARE / **Public Information:** 1-888-5-DONATE / www.life-source.org
REGIONAL OFFICES Wells Fargo Center, 21 First Street SW, Suite 310, Rochester, Minnesota 55902-3007
1100 East 21st Street, sixth floor, Sioux Falls, South Dakota 57105-1020

#5

90216.0103
Title.

Prepared by the Legislative Council staff for
Representative Weisz
April 22, 2009

PROPOSED AMENDMENTS TO SENATE BILL NO. 2195

That the House recede from its amendments as printed on page 932 of the Senate Journal and page 1010 of the House Journal and that Senate Bill No. 2195 be amended as follows:

Page 1, line 1, after "reenact" insert "subsection 3 of section 23-06.6-13 and"

Page 1, line 2, after the first "to" insert "revisions and"

Page 1, after line 3, insert:

"**SECTION 1. AMENDMENT.** Subsection 3 of section 23-06.6-13 of the North Dakota Century Code is amended and reenacted as follows:

3. When a hospital refers an individual at or near death to a procurement organization, the organization may conduct any reasonable examination necessary to ensure the medical suitability of a part that is or could be the subject of an anatomical gift for transplantation, therapy, research, or education from a donor or a prospective donor. During the examination period, measures necessary to ensure the medical suitability of the part may not be withdrawn unless the hospital or procurement organization knows that the individual expressed a contrary intent or the measures are harmful to an individual who is living and whose death is imminent."

Page 2, line 4, after the underscored period insert "If involved in resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the perspective donor's wishes and religious or moral beliefs as stated orally or as contained in the declaration or advance health care directive."

Page 2, line 5, after the underscored period insert "If conflict is not resolved expeditiously, the direction of the declaration or advance directive controls."

Page 2, line 10, replace "contraindicated" with "harmful to an individual who is living and whose death is imminent."

Page 2, remove line 11

Renumber accordingly

#6

Lee, Judy E.

From: Susan Mau Larson [smlarson@life-source.org]
Sent: Wednesday, April 22, 2009 8:54 PM
To: Lee, Judy E.
Cc: kjohnson@zkslaw.com
Subject: SB 2195

Senator Lee,

Thank you for all of your help and support with SB 2195. I know Judge Hagerty told you I might be at the hearing tomorrow. Unfortunately I wasn't able to make it out tonight. Kara Johnson will be representing us and she is well-versed on the issues and concerns.

Judge Hagerty also mentioned your question about the number of states who have adopted the UAGA. So far 36 states have adopted it and 8 more have introduced it. A map of the enactments can be found on-line at http://www.anatomicalgiftact.org/DesktopDefault.aspx?tabindex=2&tabid=72.

If you have any more questions I can answer, please don't hesitate to contact me. Thank you.

Susan Mau Larson
Director, Public Affairs
LifeSource
2550 University Ave W, Suite 315S
St. Paul, MN 55114
651-603-7852
612-968-2940 (cell)

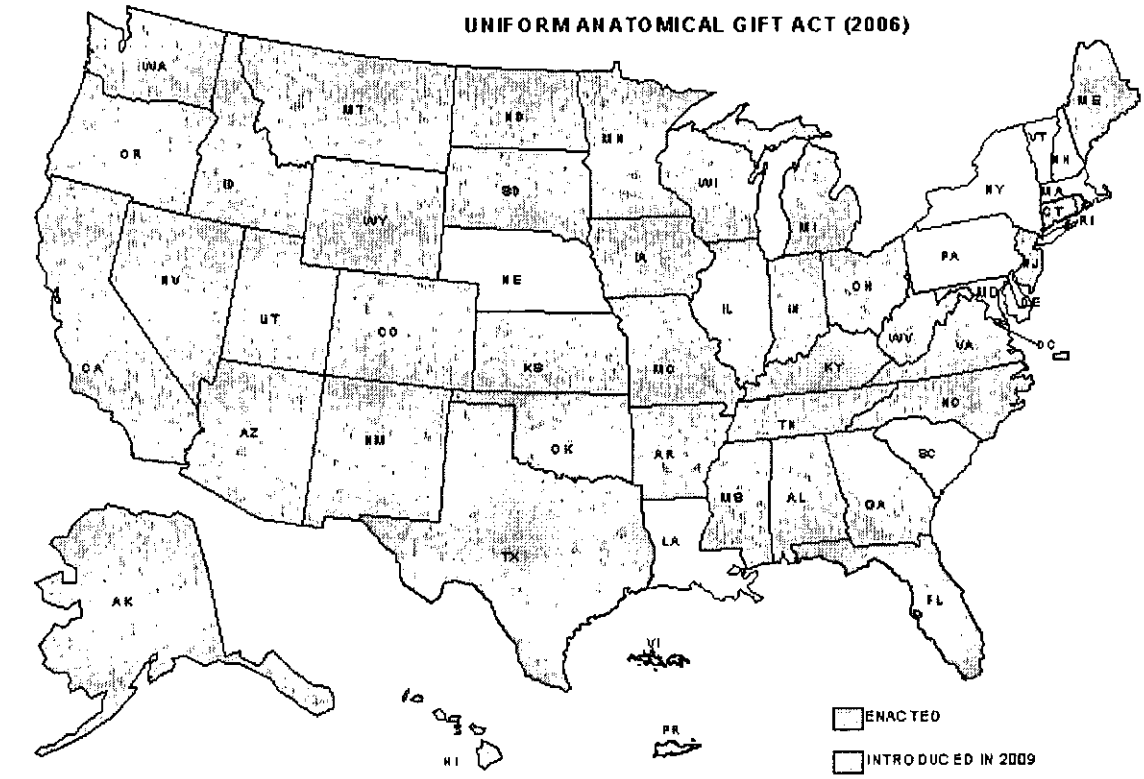
[redacted]e lives... register to be an organ and tissue donor.

[redacted]

Uniform Anatomical Gift Act

The National Conference of Commissioners on Uniform State Laws

Enactment Status Map



March 27, 2009

2009 Introductions and Enactments

Connecticut : Introduced as HB 6677 in 2009 - Joint Public Health
Florida : Introduced as SB 492/HB209 in 2009 - Senate Health
Illinois : Introduced as HB 1349 in 2009 - House Judiciary
Kentucky : Introduced as SB 25 in 2009 - Senate Judiciary
Oklahoma : Introduced as SB 622 in 2009 - Passed House Judiciary
Puerto Rico : Introduced as SB 2473 in 2009 - Introduced
South Carolina : Introduced as SB 407/HB 3491 in 2009 - Passed Both Houses
Texas : Introduced as HB 2027 in 2009 - House Health
Wyoming : Introduced as SB 86 in 2009 - ENACTED

2008 Enactments

Alabama : Introduced as HB476/SB379 in 2007-08 - ENACTED
Alaska : Introduced as SB 181 in 2007-08 - ENACTED
District of Columbia : Introduced as B17-58 in 2007-08 - ENACTED
Georgia : Introduced as SB 405 in 2007-08 - ENACTED
Hawaii : Introduced as HB 2139 in 2007-08 - ENACTED
Maine : Introduced as LD 1505 in 2007-08 - ENACTED
Maryland : Introduced as HB 906 and SB 766 - Died in Committee
Michigan : Introduced as HB 4940 in 2007-08 - ENACTED
Mississippi :Introduced as HB 1075 in 2007-08 - ENACTED
Missouri : Introduced as HB 2106/SB1139 in 2007-08 - ENACTED
New Jersey : Introduced as SB 754 in 2007-08 - ENACTED
Ohio: Introduced as HB 529 - ENACTED
Washington : Introduced as SB 5657/HB 1637 in 2007-08 - ENACTED
West Virginia : Introduced as HB4304/SB341 in 2007-08 - ENACTED
Wisconsin : Introduced as AB 570 in 2007-08 - ENACTED

2007 Enactments

The following states enacted the Revised Uniform Anatomical Gift Act in 2007:

Arizona, Arkansas, California, Colorado, Idaho, Indiana, Iowa, Kansas, Minnesota, Montana, Nevada, New Mexico, North Dakota, North Carolina, Oregon, Rhode Island, South Dakota, Tennessee, Utah, and Virginia.

111 N. Wabash Ave., Suite 1010
Chicago, Illinois 60602
tel: (312) 450-6600 | fax: (312) 450-6601 | e-mail: uaga@nccusl.org

#7

CHAPTER 23-06.6
UNIFORM ANATOMICAL GIFT ACT

23-06.6-01. Definitions. As used in this chapter, unless the context requires otherwise:

1. "Adult" means an individual who is eighteen years of age or older.

2. "Agent" means an individual:

   a. Authorized to make health care decisions on the principal's behalf by a power of attorney for health care; or

   b. Expressly authorized to make an anatomical gift on the principal's behalf by any other record signed by the principal.

3. "Anatomical gift" means a donation of all or part of a human body to take effect after the donor's death for the purpose of transplantation, therapy, research, or education.

4. "Decedent" means a deceased individual whose body or part is or may be the source of an anatomical gift. The term includes a stillborn infant and, subject to restrictions imposed by law other than this chapter, a fetus.

5. "Disinterested witness" means a witness other than the spouse, child, parent, sibling, grandchild, grandparent, or guardian of the individual who makes, amends, revokes, or refuses to make an anatomical gift or another adult who exhibited special care and concern for the individual. The term does not include a person to which an anatomical gift could pass under section 23-06.6-10.

6. "Document of gift" means a donor card or other record used to make an anatomical gift. The term includes a statement or symbol on a driver's license, identification card, or donor registry.

7. "Donor" means an individual whose body or part is the subject of an anatomical gift.

8. "Donor registry" means a data base that contains records of anatomical gifts and amendments to or revocations of anatomical gifts.

9. "Driver's license" means a license or permit issued by the department of transportation to operate a vehicle regardless of whether conditions are attached to the license or permit.

10. "Eye bank" means a person that is licensed, accredited, or regulated under federal or state law to engage in the recovery, screening, testing, processing, storage, or distribution of human eyes or portions of human eyes.

11. "Guardian" means a person appointed by a court to make decisions regarding the support, care, education, health, or welfare of an individual. The term does not include a guardian ad litem.

12. "Hospital" means a facility licensed as a hospital under the law of any state or a facility operated as a hospital by the United States, a state, or a subdivision of a state.

13. "Identification card" means an identification card issued by the department of transportation.

14. "Know" means to have actual knowledge.

15. "Minor" means an individual who is under eighteen years of age.

16. "Organ procurement organization" means a person designated by the secretary of the United States department of health and human services as an organ procurement organization.

17. "Parent" means a parent whose parental rights have not been terminated.

18. "Part" means an organ, an eye, or tissue of a human being. The term does not include the whole body.

19. "Physician" means an individual authorized to practice medicine or osteopathy under the law of any state.

20. "Procurement organization" means an eye bank, an organ procurement organization, or a tissue bank.

21. "Prospective donor" means an individual who is dead or near death and has been determined by a procurement organization to have a part that could be medically suitable for transplantation, therapy, research, or education. The term does not include an individual who has made a refusal.

22. "Reasonably available" means able to be contacted by a procurement organization without undue effort and willing and able to act in a timely manner consistent with existing medical criteria necessary for the making of an anatomical gift.

23. "Recipient" means an individual into whose body a decedent's part has been or is intended to be transplanted.

24. "Record" means information that is inscribed on a tangible medium or that is stored in an electronic or other medium and is retrievable in perceivable form.

25. "Refusal" means an intention not to make an anatomical gift of an individual's body or part expressed by the individual in accordance with section 23-06.6-06 or which expressly states an intent to bar other persons from making an anatomical gift of an individual's body or part.

26. "Sign" means, with the present intent to authenticate or adopt a record:

    a. To execute or adopt a tangible symbol; or

    b. To attach to or logically associate with the record an electronic symbol, sound, or process.

27. "Technician" means an individual determined to be qualified to remove or process parts by an appropriate organization that is licensed, accredited, or regulated under federal or state law. The term includes an enucleator.

28. "Tissue" means a portion of the human body other than an organ or an eye. The term does not include blood unless the blood is donated for the purpose of research or education.

29. "Tissue bank" means a person that is licensed, accredited, or regulated under federal or state law to engage in the recovery, screening, testing, processing, storage, or distribution of tissue.

30. "Transplant hospital" means a hospital that furnishes organ transplants and other medical and surgical specialty services required for the care of transplant patients.

23-06.6-02. Applicability. This chapter applies to an anatomical gift or amendment to, revocation of, or refusal to make an anatomical gift, whenever made.

23-06.6-03. Who may make an anatomical gift before donor's death. Subject to section 23-06.6-07, an anatomical gift of a donor's body or part may be made during the life of the donor for the purpose of transplantation, therapy, research, or education in the manner provided in section 23-06.6-04 by:

1. The donor, if the donor is an adult or if the donor is a minor and is:

   a. Emancipated; or

   b. Authorized under state law to apply for a driver's license because the donor is at least fourteen years of age;

2. An agent of the donor, unless the power of attorney for health care or other record prohibits the agent from making an anatomical gift;

3. A parent of the donor, if the donor is an unemancipated minor; or

4. The donor's guardian.

23-06.6-04. Manner of making anatomical gift before donor's death.

1. A donor may make an anatomical gift:

   a. By authorizing a statement or symbol indicating that the donor has made an anatomical gift to be imprinted on the donor's driver's license or identification card;

   b. In a will;

   c. During a terminal illness or injury of the donor, by any form of communication addressed to at least two adults, at least one of whom is a disinterested witness; or

   d. As provided in subsection 2.

2. A donor or other person authorized to make an anatomical gift under section 23-06.6-03 may make a gift by a donor card or other record signed by the donor or other person making the gift or by authorizing that a statement or symbol indicating that the donor has made an anatomical gift be included on a donor registry. If the donor or other person is physically unable to sign a record, the record may be signed by another individual at the direction of the donor or other person and must:

   a. Be witnessed by at least two adults, at least one of whom is a disinterested witness, who have signed at the request of the donor or the other person; and

   b. State that it has been signed and witnessed as provided in subdivision a.

3. Revocation, suspension, expiration, or cancellation of a driver's license or identification card upon which an anatomical gift is indicated does not invalidate the gift.

4. An anatomical gift made by will takes effect upon the donor's death whether or not the will is probated. Invalidation of the will after the donor's death does not invalidate the gift.

23-06.6-05. Amending or revoking anatomical gift before donor's death.

1. Subject to section 23-06.6-07, a donor or other person authorized to make an anatomical gift under section 23-06.6-03 may amend or revoke an anatomical gift by:

   a. A record signed by:

      (1) The donor;

      (2) The other person; or

      (3) Subject to subsection 2, another individual acting at the direction of the donor or the other person if the donor or other person is physically unable to sign; or

   b. A later-executed document of gift that amends or revokes a previous anatomical gift or portion of an anatomical gift, either expressly or by inconsistency.

2. A record signed pursuant to paragraph 3 of subdivision a of subsection 1 must:

   a. Be witnessed by at least two adults, at least one of whom is a disinterested witness, who have signed at the request of the donor or the other person; and

   b. State that it has been signed and witnessed as provided in subdivision a.

3. Subject to section 23-06.6-07, a donor or other person authorized to make an anatomical gift under section 23-06.6-03 may revoke an anatomical gift by the destruction or cancellation of the document of gift, or the portion of the document of gift used to make the gift, with the intent to revoke the gift.

4. A donor may amend or revoke an anatomical gift that was not made in a will by any form of communication during a terminal illness or injury addressed to at least two adults, at least one of whom is a disinterested witness.

5. A donor who makes an anatomical gift in a will may amend or revoke the gift in the manner provided for amendment or revocation of wills or as provided in subsection 1.

23-06.6-06. Refusal to make anatomical gift - Effect of refusal.

1. An individual may refuse to make an anatomical gift of the individual's body or part by:

   a. A record signed by:

      (1) The individual; or

      (2) Subject to subsection 2, another individual acting at the direction of the individual if the individual is physically unable to sign;

   b. The individual's will regardless of whether the will is admitted to probate or invalidated after the individual's death; or

   c. Any form of communication made by the individual during the individual's terminal illness or injury addressed to at least two adults, at least one of whom is a disinterested witness.

2. A record signed pursuant to paragraph 2 of subdivision a of subsection 1 must:

a. Be witnessed by at least two adults, at least one of whom is a disinterested witness, who have signed at the request of the individual; and

b. State that it has been signed and witnessed as provided in subdivision a.

3. An individual who has made a refusal may amend or revoke the refusal:

a. In the manner provided in subsection 1 for making a refusal;

b. By subsequently making an anatomical gift pursuant to section 23-06.6-04 which is inconsistent with the refusal; or

c. By destroying or canceling the record evidencing the refusal, or the portion of the record used to make the refusal, with the intent to revoke the refusal.

4. Except as otherwise provided in subsection 8 of section 23-06.6-07, in the absence of an express, contrary indication by the individual set forth in the refusal, an individual's unrevoked refusal to make an anatomical gift of the individual's body or part bars all other persons from making an anatomical gift of the individual's body or part.

23-06.6-07. Preclusive effect of anatomical gift, amendment, or revocation.

1. Except as otherwise provided in subsection 7 and subject to subsection 6, in the absence of an express, contrary indication by the donor, a person other than the donor is barred from making, amending, or revoking an anatomical gift of a donor's body or part if the donor made an anatomical gift of the donor's body or part under section 23-06.6-04 or an amendment to an anatomical gift of the donor's body or part under section 23-06.6-05.

2. A donor's revocation of an anatomical gift of the donor's body or part under section 23-06.6-05 is not a refusal and does not bar another person specified in section 23-06.6-03 or 23-06.6-08 from making an anatomical gift of the donor's body or part under section 23-06.6-04 or 23-06.6-09.

3. If a person other than the donor makes an unrevoked anatomical gift of the donor's body or part under section 23-06.6-04 or an amendment to an anatomical gift of the donor's body or part under section 23-06.6-05, another person may not make, amend, or revoke the gift of the donor's body or part under section 23-06.6-09.

4. A revocation of an anatomical gift of a donor's body or part under section 23-06.6-05 by a person other than the donor does not bar another person from making an anatomical gift of the body or part under section 23-06.6-04 or 23-06.6-09.

5. In the absence of an express, contrary indication by the donor or other person authorized to make an anatomical gift under section 23-06.6-03, an anatomical gift of a part is neither a refusal to give another part nor a limitation on the making of an anatomical gift of another part at a later time by the donor or another person.

6. In the absence of an express, contrary indication by the donor or other person authorized to make an anatomical gift under section 23-06.6-03, an anatomical gift of a part for one or more of the purposes set forth in section 23-06.6-03 is not a limitation on the making of an anatomical gift of the part for any of the other purposes by the donor or any other person under section 23-06.6-04 or 23-06.6-09.

7. If a donor who is an unemancipated minor dies, a parent of the donor who is reasonably available may revoke or amend an anatomical gift of the donor's body or part.

8. If an unemancipated minor who signed a refusal dies, a parent of the minor who is reasonably available may revoke the minor's refusal.

23-06.6-08. Who may make anatomical gift of decedent's body or part.

1. Subject to subsections 2 and 3 and unless barred by section 23-06.6-06 or 23-06.6-07, an anatomical gift of a decedent's body or part for the purpose of transplantation, therapy, research, or education may be made by any member of the following classes of persons who is reasonably available, in the order of priority listed:

   a. An agent of the decedent at the time of death who could have made an anatomical gift under subsection 2 of section 23-06.6-03 immediately before the decedent's death;

   b. The spouse of the decedent;

   c. Adult children of the decedent;

   d. Parents of the decedent;

   e. Adult siblings of the decedent;

   f. Adult grandchildren of the decedent;

   g. Grandparents of the decedent;

   h. An adult who exhibited special care and concern for the decedent;

   i. The persons who were acting as the guardians of the decedent at the time of death; and

   j. Any other person having the authority to dispose of the decedent's body.

2. If there is more than one member of a class listed in subdivision a, c, d, e, f, g, or i of subsection 1 entitled to make an anatomical gift, an anatomical gift may be made by a member of the class unless that member or a person to which the gift may pass under section 23-06.6-10 knows of an objection by another member of the class. If an objection is known, the gift may be made only by a majority of the members of the class who are reasonably available.

3. A person may not make an anatomical gift if, at the time of the decedent's death, a person in a prior class under subsection 1 is reasonably available to make or to object to the making of an anatomical gift.

23-06.6-09. Manner of making, amending, or revoking anatomical gift of decedent's body or part.

1. A person authorized to make an anatomical gift under section 23-06.6-08 may make an anatomical gift by a document of gift signed by the person making the gift or by that person's oral communication that is electronically recorded or is contemporaneously reduced to a record and signed by the individual receiving the oral communication.

2. Subject to subsection 3, an anatomical gift by a person authorized under section 23-06.6-08 may be amended or revoked orally or in a record by any member of a prior class who is reasonably available. If more than one member of the prior class is reasonably available, the gift made by a person authorized under section 23-06.6-08 may be:

a. Amended only if a majority of the reasonably available members agree to the amending of the gift; or

b. Revoked only if a majority of the reasonably available members agree to the revoking of the gift or if they are equally divided as to whether to revoke the gift.

3. A revocation under subsection 2 is effective only if, before an incision has been made to remove a part from the donor's body or before invasive procedures have begun to prepare the recipient, the procurement organization, transplant hospital, or physician or technician knows of the revocation.

23-06.6-10. Persons that may receive anatomical gift - Purpose of anatomical gift.

1. An anatomical gift may be made to the following persons named in the document of gift:

   a. A hospital; accredited medical school, dental school, college, or university; organ procurement organization; or other appropriate person for research or education;

   b. Subject to subsection 2, an individual designated by the person making the anatomical gift if the individual is the recipient of the part; or

   c. An eye bank or tissue bank.

2. If an anatomical gift to an individual under subdivision b of subsection 1 cannot be transplanted into the individual, the part passes in accordance with subsection 7 in the absence of an express, contrary indication by the person making the anatomical gift.

3. If an anatomical gift of one or more specific parts or of all parts is made in a document of gift that does not name a person described in subsection 1 but identifies the purpose for which an anatomical gift may be used, the following rules apply:

   a. If the part is an eye and the gift is for the purpose of transplantation or therapy, the gift passes to the appropriate eye bank.

   b. If the part is tissue and the gift is for the purpose of transplantation or therapy, the gift passes to the appropriate tissue bank.

   c. If the part is an organ and the gift is for the purpose of transplantation or therapy, the gift passes to the appropriate organ procurement organization as custodian of the organ.

   d. If the part is an organ, an eye, or tissue and the gift is for the purpose of research or education, the gift passes to the appropriate procurement organization.

4. For the purpose of subsection 3, if there is more than one purpose of an anatomical gift set forth in the document of gift but the purposes are not set forth in any priority, the gift must be used for transplantation or therapy, if suitable. If the gift cannot be used for transplantation or therapy, the gift may be used for research or education.

5. If an anatomical gift of one or more specific parts is made in a document of gift that does not name a person described in subsection 1 and does not identify the purpose of the gift, the gift may be used only for transplantation or therapy, and the gift passes in accordance with subsection 7.

6. If a document of gift specifies only a general intent to make an anatomical gift by words such as "donor", "organ donor", or "body donor", or by a symbol or statement of similar import, the gift may be used only for transplantation or therapy, and the gift passes in accordance with subsection 7.

7. For purposes of subsections 2, 5, and 6 the following rules apply:

   a. If the part is an eye, the gift passes to the appropriate eye bank.

   b. If the part is tissue, the gift passes to the appropriate tissue bank.

   c. If the part is an organ, the gift passes to the appropriate organ procurement organization as custodian of the organ.

8. An anatomical gift of an organ for transplantation or therapy, other than an anatomical gift under subdivision b of subsection 1, passes to the organ procurement organization as custodian of the organ.

9. If an anatomical gift does not pass pursuant to subsection 1, 2, 3, 4, 5, 6, 7, or 8 or the decedent's body or part is not used for transplantation, therapy, research, or education, custody of the body or part passes to the person under obligation to dispose of the body or part.

10. A person may not accept an anatomical gift if the person knows that the gift was not effectively made under section 23-06.6-04 or 23-06.6-09 or if the person knows that the decedent made a refusal under section 23-06.6-06 that was not revoked. For purposes of this subsection, if a person knows that an anatomical gift was made on a document of gift, the person is deemed to know of any amendment or revocation of the gift or any refusal to make an anatomical gift on the same document of gift.

11. Except as otherwise provided in subdivision b of subsection 1, nothing in this chapter affects the allocation of organs for transplantation or therapy.

23-06.6-11. Search and notification.

1. The following persons shall make a reasonable search of an individual who the person reasonably believes is dead or near death for a document of gift or other information identifying the individual as a donor or as an individual who made a refusal:

   a. A law enforcement officer, firefighter, paramedic, or other emergency rescuer finding the individual; and

   b. If no other source of the information is immediately available, a hospital, as soon as practical after the individual's arrival at the hospital.

2. If a document of gift or a refusal to make an anatomical gift is located by the search required by subdivision a of subsection 1 and the individual or deceased individual to whom it relates is taken to a hospital, the person responsible for conducting the search shall send the document of gift or refusal to the hospital.

3. A person is not subject to criminal or civil liability for failing to discharge the duties imposed by this section but may be subject to administrative sanctions.

23-06.6-12. Delivery of document of gift not required - Right to examine.

1. A document of gift need not be delivered during the donor's lifetime to be effective.

2. Upon or after an individual's death, a person in possession of a document of gift or a refusal to make an anatomical gift with respect to the individual shall allow examination and copying of the document of gift or refusal by a person authorized to make or object to the making of an anatomical gift with respect to the individual or by a person to which the gift could pass under section 23-06.6-10.

23-06.6-13. Rights and duties of procurement organization and others.

1. When a hospital refers an individual at or near death to a procurement organization, the organization shall make a reasonable search of the records of the department of transportation and any donor registry that it knows exists for the geographical area in which the individual resides to ascertain whether the individual has made an anatomical gift.

2. A procurement organization must be allowed reasonable access to information in the records of the department of transportation to ascertain whether an individual at or near death is a donor.

3. When a hospital refers an individual at or near death to a procurement organization, the organization may conduct any reasonable examination necessary to ensure the medical suitability of a part that is or could be the subject of an anatomical gift for transplantation, therapy, research, or education from a donor or a prospective donor. During the examination period, measures necessary to ensure the medical suitability of the part may not be withdrawn unless the hospital or procurement organization knows that the individual expressed a contrary intent.

4. Unless prohibited by law other than this chapter, at any time after a donor's death, the person to which a part passes under section 23-06.6-10 may conduct any reasonable examination necessary to ensure the medical suitability of the body or part for its intended purpose.

5. Unless prohibited by law other than this chapter, an examination under subsection 3 or 4 may include an examination of all medical and dental records of the donor or prospective donor.

6. Upon the death of a minor who was a donor or had signed a refusal, unless a procurement organization knows the minor is emancipated, the procurement organization shall conduct a reasonable search for the parents of the minor and provide the parents with an opportunity to revoke or amend the anatomical gift or revoke the refusal.

7. Upon referral by a hospital under subsection 1, a procurement organization shall make a reasonable search for any person listed in section 23-06.6-08 having priority to make an anatomical gift on behalf of a prospective donor. If a procurement organization receives information that an anatomical gift to any other person was made, amended, or revoked, it shall promptly advise the other person of all relevant information.

8. Subject to subsection 9 of section 23-06.6-10 and section 23-06.6-22, the rights of the person to which a part passes under section 23-06.6-10 are superior to the rights of all others with respect to the part. The person may accept or reject an anatomical gift in whole or in part. Subject to the terms of the document of gift and this chapter, a person that accepts an anatomical gift of an entire body may allow embalming, burial or cremation, and use of remains in a funeral service. If the gift is of a part, the person to which the part passes under section 23-06.6-11, upon the death of the donor and before embalming, burial, or cremation, shall cause the part to be removed without unnecessary mutilation.

9. Neither the physician who attends the decedent at death nor the physician who determines the time of the decedent's death may participate in the procedures for removing or transplanting a part from the decedent.

10. A physician or technician may remove a donated part from the body of a donor which the physician or technician is qualified to remove.

23-06.6-14. Coordination of procurement and use. Each hospital in this state shall enter into agreements or affiliations with procurement organizations for coordination of procurement and use of anatomical gifts.

23-06.6-15. Sale or purchase of parts prohibited - Penalty.

1. Except as otherwise provided in subsection 2, a person that for valuable consideration knowingly purchases or sells a part for transplantation or therapy if removal of a part from an individual is intended to occur after the individual's death commits a class B misdemeanor.

2. A person may charge a reasonable amount for the removal, processing, preservation, quality control, storage, transportation, implantation, or disposal of a part.

23-06.6-16. Other prohibited act - Penalty. A person that, in order to obtain a financial gain, intentionally falsifies, forges, conceals, defaces, or obliterates a document of gift, an amendment or revocation of a document of gift, or a refusal commits a class B misdemeanor.

23-06.6-17. Immunity.

1. A person that acts in accordance with this chapter or with the applicable anatomical gift law of another state, or attempts in good faith to do so, is not liable for the act in a civil action, criminal prosecution, or administrative proceeding.

2. Neither the person making an anatomical gift nor the donor's estate is liable for any injury or damage that results from the making or use of the gift.

3. In determining whether an anatomical gift has been made, amended, or revoked under this chapter, a person may rely upon representations of an individual listed in subdivision b, c, d, e, f, g, or h of subsection 1 of section 23-06.6-08 relating to the individual's relationship to the donor or prospective donor unless the person knows that the representation is untrue.

23-06.6-18. Law governing validity - Choice of law as to execution of document of gift - Presumption of validity.

1. A document of gift is valid if executed in accordance with:

   a. This chapter;

   b. The laws of the state or country where the document of gift was executed; or

   c. The laws of the state or country where the person making the anatomical gift was domiciled, has a place of residence, or was a national at the time the document of gift was executed.

2. If a document of gift is valid under this section, the law of this state governs the interpretation of the document of gift.

3. A person may presume that a document of gift or amendment of an anatomical gift is valid unless that person knows that it was not validly executed or was revoked.

23-06.6-19. Donor registry.

1. The state department of health may establish or contract for the establishment of a donor registry.

2. The department of transportation shall cooperate with a person that administers any donor registry that this state establishes, contracts for, or recognizes for the purpose of transferring to the donor registry all relevant information regarding a donor's making, amendment to, or revocation of an anatomical gift.

3. A donor registry must:

   a. Allow a donor or other person authorized under section 23-06.6-04 to include on the donor registry a statement or symbol that the donor has made, amended, or revoked an anatomical gift;

   b. Be accessible to a procurement organization to allow it to obtain relevant information on the donor registry to determine, at or near death of the donor or a prospective donor, whether the donor or prospective donor has made, amended, or revoked an anatomical gift; and

   c. Be accessible for purposes of subdivisions a and b seven days a week on a twenty-four-hour basis.

4. Personally identifiable information on a donor registry about a donor or prospective donor may not be used or disclosed without the express consent of the donor, prospective donor, or person that made the anatomical gift for any purpose other than to determine, at or near death of the donor or prospective donor, whether the donor or prospective donor has made, amended, or revoked an anatomical gift.

5. This section does not prohibit any person from creating or maintaining a donor registry that is not established by or under contract with the state. Any such registry must comply with subsections 3 and 4.

23-06.6-20. Effect of anatomical gift on advance health care directive.

1. In this section:

   a. "Advance health care directive" means a health care directive under chapter 23-06.5, a power of attorney for health care, or a record signed by a prospective donor containing the prospective donor's direction concerning a health care decision for the prospective donor.

   b. "Declaration" means a record signed by a prospective donor specifying the circumstances under which a life support system may be withheld or withdrawn from the prospective donor.

   c. "Health care decision" means any decision made regarding the health care of the prospective donor.

2. If a prospective donor has a declaration or advance health care directive, measures necessary to ensure the medical suitability of an organ for transplantation or therapy may not be withheld or withdrawn from the prospective donor, unless the declaration or advance health care directive expressly provides to the contrary.

23-06.6-21. Cooperation between coroner or medical examiner and a procurement organization.

1. A coroner or medical examiner shall cooperate with procurement organizations to maximize the opportunity to recover anatomical gifts for the purpose of transplantation, therapy, research, or education.

2. If a coroner or medical examiner receives notice from a procurement organization that an anatomical gift might be available or was made with respect to a decedent whose body is under the jurisdiction of the coroner or medical examiner and a post-mortem examination is going to be performed, unless the coroner or medical examiner denies recovery in accordance with section 23-06.6-22, the coroner or medical examiner or designee of the coroner or medical examiner shall conduct a post-mortem examination of the body or the part in a manner and within a period compatible with its preservation for the purposes of the gift.

3. A part may not be removed from the body of a decedent under the jurisdiction of a coroner or medical examiner for transplantation, therapy, research, or education unless the part is the subject of an anatomical gift. The body of a decedent under the jurisdiction of the coroner or medical examiner may not be delivered to a person for research or education unless the body is the subject of an anatomical gift. This subsection does not preclude a coroner or medical examiner from performing the medicolegal investigation upon the body or parts of a decedent under the jurisdiction of the coroner or medical examiner.

23-06.6-22. Facilitation of anatomical gift from decedent whose body is under jurisdiction of coroner or medical examiner.

1. Upon request of a procurement organization, a coroner or medical examiner shall release to the procurement organization the name, contact information, and available medical and social history of a decedent whose body is under the jurisdiction of the coroner or medical examiner. If the decedent's body or part is medically suitable for transplantation, therapy, research, or education, the coroner or medical examiner shall release post-mortem examination results to the procurement organization. The procurement organization may make a subsequent disclosure of the post-mortem examination results or other information received from the coroner or medical examiner only if relevant to transplantation or therapy.

2. The coroner or medical examiner may conduct a medicolegal examination by reviewing all medical records, laboratory test results, x-rays, other diagnostic results, and other information that any person possesses about a donor or prospective donor whose body is under the jurisdiction of the coroner or medical examiner which the coroner or medical examiner determines may be relevant to the investigation.

3. A person that has any information requested by a coroner or medical examiner pursuant to subsection 2 shall provide that information as expeditiously as possible to allow the coroner or medical examiner to conduct the medicolegal investigation within a period compatible with the preservation of parts for the purpose of transplantation, therapy, research, or education.

4. If an anatomical gift has been or might be made of a part of a decedent whose body is under the jurisdiction of the coroner or medical examiner and a post-mortem examination is not required, or the coroner or medical examiner determines that a post-mortem examination is required but that the recovery of the part that is the subject of an anatomical gift will not interfere with the examination, the coroner or medical examiner and procurement organization shall cooperate in the timely removal of the part from the decedent for the purpose of transplantation, therapy, research, or education.

5. If an anatomical gift of a part from the decedent under the jurisdiction of the coroner or medical examiner has been or might be made, but the coroner or medical examiner initially believes that the recovery of the part could interfere with the

post-mortem investigation into the decedent's cause or manner of death, the coroner or medical examiner shall consult with the procurement organization or physician or technician designated by the procurement organization about the proposed recovery. The procurement organization shall provide the coroner or medical examiner with all information the organization has which could relate to the cause or manner of the decedent's death. After consultation, the coroner or medical examiner may allow the recovery.

6. Following the consultation under subsection 5, in the absence of mutually agreed-upon protocols to resolve conflict between the coroner or medical examiner and the procurement organization, if the coroner or medical examiner intends to deny recovery of an organ for transplantation, the coroner or medical examiner or designee of the coroner or medical examiner, at the request of the procurement organization, shall attend the removal procedure for the part before making a final determination not to allow the procurement organization to recover the part. During the removal procedure, the coroner or medical examiner or designee of the coroner or medical examiner may allow recovery by the procurement organization to proceed, or, if the coroner or medical examiner or designee of the coroner or medical examiner reasonably believes that the part may be involved in determining the decedent's cause or manner of death, deny recovery by the procurement organization.

7. If the coroner or medical examiner or designee of the coroner or medical examiner denies recovery under subsection 6, the coroner or medical examiner or designee of the coroner or medical examiner shall:

   a. Explain in a record the specific reasons for not allowing recovery of the part;

   b. Include the specific reasons in the records of the coroner or medical examiner; and

   c. Provide a record with the specific reasons to the procurement organization.

8. If the coroner or medical examiner or designee of the coroner or medical examiner allows recovery of a part under subsection 4, 5, or 6, the procurement organization, upon request, shall cause the physician or technician who removes the part to provide the coroner or medical examiner with a record describing the condition of the part, a biopsy, a photograph, and any other information and observations that would assist in the post-mortem examination.

9. If a coroner or medical examiner or designee of a coroner or medical examiner is required to be present at a removal procedure under subsection 6, upon request the procurement organization requesting the recovery of the part shall reimburse the coroner or medical examiner or designee of the coroner or medical examiner for the additional costs incurred in complying with subsection 6.

23-06.6-23. Relation to Electronic Signatures in Global and National Commerce Act. This chapter modifies, limits, and supersedes the federal Electronic Signatures in Global and National Commerce Act [15 U.S.C. 7001 et seq.], but does not modify, limit, or supersede section 101(a) of that Act [15 U.S.C. 7001], or authorize electronic delivery of any of the notices described in section 103(b) of that Act [15 U.S.C. 7003(b)].

Karen Johnson 4-23-09 #8

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2195

That the House recede from its amendments on page 932 of the Senate Journal and page 1010 of the House Journal and that Senate Bill No. 2195 be amended as follows:

Page 2, line 4, after the underscored period insert "If involved in resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs as stated orally or as contained in the declaration or advance health care directive."

Page 2, line 5, after the underscored period insert "If conflict is not resolved expeditiously, the direction of the declaration or advance directive shall control."

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Title.

Prepared by the Legislative Council staff for
Senator Erbele
April 22, 2009

PROPOSED AMENDMENTS TO SENATE BILL NO. 2195

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Page 2, line 5, after the underscored period insert "If involved in resolving the conflict, the agent or other person authorized by law shall make the decision in accordance with the agent's or person's knowledge of the prospective donor's wishes and religious or moral beliefs as stated orally or as contained in the declaration or advance health care directive."

Renumber accordingly