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ROLL NUMBER

DESCRIPTION

2163

2007 SENATE HUMAN SERVICES

SB 2163

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2163

Senate Human Services Committee

Check here for Conference Committee

Hearing Date: 1-17-07

Recorder Job Number: 1273, 1303, 1304

Committee Clerk Signature

Mary K Monson

Minutes:

Senator J. Lee, Chairman, opened the hearing on SB 2163 relating to the revised Uniform Anatomical Gift Act.

Senator Ralph Kilzer (Dist. #47) introduced SB 2163 as prime sponsor. He talked about both the morbidity and mortality aspects of transplants. This legislation is meant to more clearly identify who can be a donor.

Judge Gail Hagerty (District Judge from Bismarck) testified in favor of SB 2163.

(Attachment #1)

Senator Dever said that now if he wants to be a donor, he puts it on his drivers license. With this he wanted to know if he would have to hire an attorney to put this together.

Judge Hagerty said the wish is that it is put on the drivers' license.

Senator Dever asked if his family could prevent it.

Judge Hagerty said that probably wouldn't be exactly a legal statement if you have made a designation of a gift. However, in many cases, family wishes are respected. This strengthens the language which is in current law and would allow your intentions to be carried through.

Senator Dever asked what happens if the family disagrees with it and argues after his death.

Judge Hagerty said it will happen pretty fast and the law will say, follow your intentions.

Senator J. Lee asked if this also applies to someone who chooses to donate their bodies to medical school.

Judge Hagerty replied yes it does.

Senator Heckaman asked if any of this mirrors any federal law.

Judge Hagerty said it coordinates well with federal law.

Senator Dever asked about minor child on page 4, line 26. Does emancipated need to be defined?

Judge Hagerty said it is. That is a legal term that is defined and people know what that means.

Emancipated is a child who is no longer under parental control.

Senator J. Lee asked about an underage mother. She is under the control of her parents, but she is in control of the baby. If the baby should not live the mother could make the choice about donating an organ. Could the grandparents of the baby overrule?

Judge Hagerty wasn't sure if it specifically addressed that.

Senator Warner asked about maintaining the integrity of the bill as presented.

Judge Hagerty said the uniform law commission is kind of one of the last state's rights according to organizations because where there are areas of law that should be the same in each state, they try to draft laws that will be acceptable to all the states. That doesn't mean they are all the same but they are looking at the big picture. There could be minor variations and it could still be a uniform law. The important thing is that people are mobile and it is important that their document of gift be good wherever they are.

Senator Pomeroy talked about the living wills which is also very helpful.

Judge Hagerty said that would be a documented gift – a statement of intention to make a gift.

Senator Warner asked if she anticipated a registry would also include genetic data that might be useful. Does it include genetic material or simply a list of donors?

Judge Hagerty replied that the registries in place now are lists of donors and their wishes.

Monica Kersting (Parent from West Fargo) testified in favor of SB 2163 and requested that the anatomical gift act go through as quickly as possible. She told the story of losing their daughter 2 ½ years ago waiting for a lung transplant. She and her husband are trying to remove roadblocks that prevent people from being donors, the things that make it a difficult process.

Loren Kersting (Parent from West Fargo) testified on behalf of his daughter who died while waiting for a lung transplant. His daughter was number 1 on the list. He is concerned about all those who are lower on the list. He feels ND has the opportunity to be the first state to pass this revised act that takes the roadblocks away.

Pat Ward (representing LifeSource) testified that organ donation is an opportunity for a person to not diminish mankind when they pass but to actually provide for assistance and help for others. One organ donor can impact as many as 50-60 lives and their families in a positive way. He told the positive story of his uncle who received a heart transplant 15 years ago. He then introduced Susan Larson, Mpls.

Susan Mau Larson (Director for Public Affairs, LifeSource) testified in support of SB 2163.

(Attachment #2)

Senator Dever asked how big is the problem and how great is the solution?

Ms. Larson said they have been working with the Dept. of Transportation. They are able to call the state and determine if donor is on their license and then share that with the family. The gap is the number of people who are not documenting their wishes. This will provide information to further enhance. Minors, 14-17 year olds, can't document their wishes to donate right now. That could be an eight year gap where they can't document their wishes.

Senator J. Lee offered information that someone who dies from an illness still may be a donor.

Senator Warner asked about transplantation in infants and the necessity for an autopsy needed to gather evidence for criminal prosecution versus the desire to expedite, as soon as possible, the transplant tissue.

Ms. Larson said they work closely in partnership with medical examiners in their region when there is a case and they are involved to try and work through that.

Bruce Levi (ND Medical Association) reported that they had worked early on with Judge Hagerty and brought the bill to their commission on ethics who reviewed it. They like it and lend their support of SB 2163.

Donna Gage (Registered Nurse) testified in support of SB 2163. (Attachment #3)

Dr. Mary Ann Sens (Professor and Chair of Pathology, UND) testified in support of SB 2163 and also highlighted some concerns she had. (Attachment #4)

Sophia Prezler from Bismarck testified on her own behalf as a concerned citizen in opposition to SB 2163.

There was no neutral testimony.

Senator J. Lee asked Judge Hagerty if she would provide additional information on previous questions.

Judge Hagerty said that after the drafting process they made several contacts with the National Association of Medical Examiners and they worked through the language. The tension is probably what would be found in other areas of the country but not in ND.

The organ procurement organization has dealt with this and it has been a problem for them particularly in NY, NJ, and sometimes in CA. In order to have some type of compromise there can be a mutually agreed upon protocol. (Meter 64:00) The issue is only an issue when recovering organs, because tissue is not in as short supply and the timing isn't as critical.

Senator Warner asked about the definition of decedent on page 2, line 10-14, and if there is a technical definition of fetus and embryo.

Judge Hagerty said that issue was discussed a lot at their last meeting. By including stillborns and fetuses in the definition of decedent this act assures that stillborns and fetuses continue to receive the statutory protection conferred by the fact, namely, that their body or parts cannot be used for transplantation, therapy research, or education without the appropriate consent.

The definition does not broaden the scope of available transport or research subject or technique. If those terms were taken out, it would be taking protection away.

Senator Warner asked for a distinction between "guardian" and "guardian ad litem" on page 3.

Judge Hagerty said that guardian ad litem is someone who is usually appointed just to represent someone during the time when a court action is pending. It's a short term assignment to represent someone's interest in court.

Senator Warner asked the medical examiner a question about the duration and viability of the tissue. Would decisions on the harvest of organs be made while the heart is still beating and the organs are still being profused with oxygen?

Dr. Sens said that was true. The person is on an artificial life support. They have been declared brain dead according protocol set forth. When a person is found dead the organs cannot be used but many tissues may be used, primarily for therapeutic purposes in contrast to life saving.

Senator Warner asked about the time frame when a tissue sample isn't viable any longer.

Dr. Sens replied the cutoff is 24 hours from the time the person was seen alive.

Senator Heckaman asked what forms of tissue are harvested.

Dr. Sens replied heart valves, bones, skin, and vascular tissue.

Senator Dever asked Judge Hagerty if they were to consider amendments to address Dr. Sens concerns would if jeopardize the uniformity of the act.

Judge Hagerty said there can be minor variations and it would still be a uniform act. She hoped it would be left as it is.

The hearing on SB 2163 was closed.

Job #1303

Senator J. Lee opened SB 2163 for discussion.

Senator Dever reported that Judge Hagerty told him if they would simply insert the words "of an organ" after the word "recovery" on page 19, line 6, that would satisfy Dr. Sens concerns.

Senator J. Lee asked if Judge Hagerty was ok with that as well.

Senator Dever said Judge Hagerty would prefer they do not include the amendment but, if they do, she would like to see the simplest kind.

The issue on page 2, line 10-12, about the inclusion of the fetus was discussed. The inclusion grants some protection.

Senator J. Lee suggested they might get some further information from Judge Hagerty on that issue.

The discussion on SB 2163 was closed.

Job #1304

Senator J. Lee opened SB 2163 for discussion and she asked Bruce Levi from the Medical Association for additional comments to make sure the current advanced directives are in sync with this bill.

Bruce Levi (Medical Association) said they reviewed a version of the bill before it was through LC. The advanced directive piece was more generic. There needs a little work done to clean

up some of the references. He offered to present a proposed amendment to address that clean up.

Senator J. Lee closed discussion on SB 2163.

2007 SENATE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2163

Senate Human Services Committee

Check here for Conference Committee

Hearing Date: 1-22-07

Recorder Job Number: 1537, 1539

Committee Clerk Signature

Mary K Monson

Minutes:

Senator J. Lee, Chairman, opened SB 2163 for discussion on an amendment and she invited Judge Hagerty to explain the amendment. One of the questions the committee had was about making sure it was synchronized with the advanced directives legislation that was passed last session. Another question was about whether or not to include the word "fetus" at the beginning.

Judge Hagerty brought amendments by Bruce Levi (Medical Association). Words were added to make sure where health care directives are talked about the statutory scheme is included. A typographical error was corrected. A change requested by Dr. Sens with regard to adding the words "of an organ" was also made.

She addressed the concern with the word decedent at the beginning of the bill using language involving a stillborn infant and fetus. The reason the language is in there is because this act talks about who could make any gift that would be made and also prohibits sale. If those words are taken out, they are taken out of the protection of the act.

Job # 1539

Senator J. Lee reopened SB 2163 for discussion.

Senator Warner said it was important to remind the committee that this is the bill that provides a greater degree of protection for the donor. He was comfortable that the language which would include stillborn infant and fetus grants greater protection under this bill than if it were deleted.

Senator Warner moved to accept the amendments prepared by the Medical Association.

Second by Senator Dever.

Roll call vote 6-0-0. Amendment accepted.

Senator Dever moved a Do Pass as Amended.

Second by Senator Pomeroy.

Roll call vote 6-0-0. Passed. Carrier is Senator Warner.

**Proposed Amendments to SB 2163
North Dakota Medical Association**

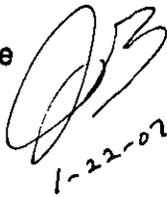
Page 8, line 26, replace "reasonable" with "reasonably"

Page 16, line 23, after "means" insert "health care directive under chapter 23-06.5," and after the second "care" insert an underscored comma

Page 17, line 4, after "declaration" insert "or advance health care directive"

Page 19, line 6, after "recovery" insert "of an organ"

Renumber accordingly



1-22-07

PROPOSED AMENDMENTS TO SENATE BILL NO. 2163

Page 8, line 26, replace "reasonable" with "reasonably"

Page 16, line 23, after "means" insert "a health care directive under chapter 23-06.5," and after the second "care" insert an underscored comma

Page 17, line 4, after "declaration" insert "or advance health care directive"

Page 19, line 6, after "recovery" insert "of an organ"

Renumber accordingly

REPORT OF STANDING COMMITTEE

SB 2163: Human Services Committee (Sen. J. Lee, Chairman) recommends **AMENDMENTS AS FOLLOWS** and when so amended, recommends **DO PASS** (6 YEAS, 0 NAYS, 0 ABSENT AND NOT VOTING). SB 2163 was placed on the Sixth order on the calendar.

Page 8, line 26, replace "reasonable" with "reasonably"

Page 16, line 23, after "means" insert "a health care directive under chapter 23-06.5," and after the second "care" insert an underscored comma

Page 17, line 4, after "declaration" insert "or advance health care directive"

Page 19, line 6, after "recovery" insert "of an organ"

Renumber accordingly

2007 HOUSE HUMAN SERVICES

SB 2163

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2163

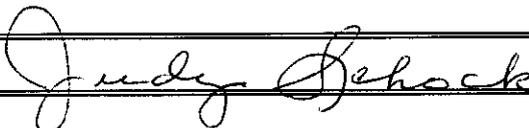
House Human Services Committee

Check here for Conference Committee

Hearing Date: March 7, 2007

Recorder Job Number: 4541

Committee Clerk Signature



Chairman Price: We will open the hearing on SB 2163.

Senator Ralph Kilzer: The anatomical gift has been revised because it has been more than 20 years since this has been updated. Many things have changed in that time including the appearance of the donor on your drivers license. The uniformed part is states are becoming more uniform in their laws. There are about 25 states that have adopted similar legislation. It is estimated that more than 7,000 people die each year in our country, waiting organ transplants. These are lives that could be saved. Ethically the recipients are the people who need them the most, and closest to death. This makes the survivor ability less. This bill makes it easier for people to donate and clarifies the legal process.

Judge Gail Hagerty of Bismarck: See attached testimony. I have worked 2 years working on this bill. In January 2006 there were more than 92,000 people on the waiting list of organ transplantation, and the list is growing. I read it is growing by 5,000 a year. The lack of organs results from a lack of organ donors. This bill has provided addition ways to make organ and tissue donations. These changes will keep ND laws keep pace with those improvements and changes. It is good for all of the states to have law that is very similar. People move around and travel around, so it is good to have uniform law. It empowers minors who are eligible to apply for a drivers license to designate an intention to be a donor, if that young person would

die before they are 18 their parents would have the final word. If they die after 18 their decision would be honored. It is encouraging donor registries and set up standards. I would think there will be federal money available to help states that don't have registries to do that. That is a helpful provision.

Representative Weisz: Is there a reason why we have decline virtually everything in here that is possibly defined in other places in code?

Judge Hagerty: I think you can't read that act with out the definition. I think this is helpful to read the whole act together.

Chairman Price: In the event that someone is looking at this, would they have to go to this part of the code and that part of the code?

Judge Hagerty: It is a uniform act and we want it read informally in all the states so if there is another definition in another part of the code it might not be the same. It is important to have these provisions. We are comfortable with the Senates amendments.

Representative Porter: Do you see adding the emergency clause to it as a problem.

Judge Hagerty: It is not a problem at all. I am getting forms ready for emergency cases. I would like it.

Pat Ward, with Bismarck law firm of Zuger Kirmis & Smith: See attached testimony:

Susan Mau Larson, Director of Public Affairs for LifeSource: See attached testimony.

Ed Christianson: In 2003 my wife passed away. She had a donor license. It was unexpected, and you don't have much time to think. When LifeSource arrived they did a wonderful job with me and my kids. It is hard to do, but that was her wishes. We have gotten something out that many do not. I have had the opportunity to meet the lady that received my wife's liver. It is a great feeling to know you are helping someone else out. If you think you are to old you are not. It is a good feeling to give.

Bruce Levi, American Medical Association: We support this bill. We were involved in the National level. I also represent the ND society of eye physicians and surgeons in ND. The uniformity among the states is what is important here, and is critical the donors wishes will be honored. Transplantation occurs across state boundaries and requires speed and efficiency if the organ plantation is successful.

Craig Lahren, Administrator for the ND Department of Health Forensic Examiners: I am here to support the bill, and I will be offering testimony for **Dr. Mary Ann Sens, who is acting state forensic examiner for the ND Department of Health.** She has also included a letter from the National Association of Medical Examiners.

Lauren Kersling: testimony left for the committee see attached.

Representative Weisz: on 2306 2607 on page 7 of the bill he asks **Judge Hagerty** to explain and define words.

Chairman Price: Is there any more testimony for SB 2163? If not we will close the hearing on SB 2163.

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2163

House Human Services Committee

Check here for Conference Committee

Hearing Date: March 14, 2007

Recorder Job Number: 5097

Committee Clerk Signature

Judith Schock

Minutes:

Rep. Damschen: I think Rep. Weisz brought up a good point in the discussion if I'm remembering. Isn't this the one that had stages of definitions? Well that is obvious. It wasn't defined in the bill. It was very obvious although some of it is not.

Rep. Price: I know they can't have all the definitions. It makes it easier to the average person.

Rep. Damschen: I can understand that too but I thought it was kind of funny how they didn't include that definition in there as well. I forget what the term was.

Rep. Price: I just remember back to how many sessions he went around in this committee. She realized that she put the Department a little in the box on a couple of things. Before we go too far, this amendment that is in front of you came out of discussion between Gale Hagerty and the Forensic Examiner. The Forensic Examiner and another person are having dinner tonight. There are further things that need to come out which we may need to go to conference for. She did like this amendment too.

Rep. Weisz: If you read the bill, the reality is the way it is set up now, you can revoke your donor license. Someone else could still decide if you are going to be an organ donor unless you spell out all of these criteria that you have to do. That is why I asked the question. There as a definition of refusal but there wasn't for identification. You can get it revoked but it doesn't

mean anything. Revocation means nothing. They can ignore it. I guess that is just a concern that I have. Under this bill everyone is a donor under implication. That is what it is doing. Someone can't do this unless you specifically spell it out. You can put organ donor on your card but if you read the bill in the language, they can just go ahead and let you specifically do that. That is my opinion. I want everyone to be an organ donor. I think there are some gray areas. Revocation does not mean a refusal; it does not bar another person from making the gift. Even though they are revoked, they can still go ahead and do it. That is my concern.

Rep. Conrad: You can revoke it but if someone else is responsible they can do it?

Rep. Weisz: That's right.

Rep. Conrad: So if you have given up your authority>

Rep. Weisz: A revocation means nothing I guess in the context of this because it does not mean a refusal. It does not bar anyone else from going ahead and donating their organs, even though you have revoked it. That is the concern I have. It's on page 3 line 26. Then you ought to look under refusal and you will see what refusal is. It has records. It has to have an adequate assigned record saying that you refused. If you don't have that anybody can donate your organs.

Rep. Kaldor: I'm curious about that. There has to be another person specified in that section that can make that decision. It isn't just you. Someone else can make that decision on your behalf. If you are lying on the table and you decide to revoke when a decision has been made. If they haven't cut you, and you say that you revoke, what happens?

Rep. Porter: Revocation was not an anatomical gift of the donor's body or part. It is not a refusal. It does not do that.

Rep. Kaldor: That is someone acting on your behalf, you aren't on the table.

Rep. Weisz: Yeah but you have revoked it but now you are saying that they can turn around and do it.

Rep. Conrad: This happened with my father. He did not have a statement as to be a donor or not. They called my mother after he passed away and asked if they could donate his eyes. She said yes. What Judge Hagerty was saying that if you revoke it, you take it back to nothing? So then if somebody is responsible later, they can say that yes it is ok. When you revoke it, someone can step in and do that.

Rep. Weisz: But if you revoke it you have made a statement. It is not a refusal.

Rep. Conrad: Is there an amendment that could help this?

Rep. Weisz: I don't know. I don't know if it is important. I don't know why that subsection 2 really has to be in there.

Rep. Kaldor: On page 5 under that provision, that pretty much says that the donor can do it.

Rep. Weisz: None of that applies though.

Rep. Kaldor: You think on page 6 that all of those subsections have to exist before the revocation occurs? I guess that I thought if the donor revokes, he revokes. The records are signed by, under subsection a, the donor. If I revoke it, it is revoked.

Rep. Weisz: That is how I interpreted it too. Refusal and revocation are separate things.

Rep. Kaldor: Revoking is taking it away. What part talks about refusal?

Rep. Weisz: On page it talks about refusal and revocation. It is not a refusal and does not bar another person from making that decision. That is my only concern.

Rep. Kaldor: That other person would have to be who is then left in charge of your remains after you are dead.

Rep. Weisz: I understand that and that is my whole thing. If a person revokes being an organ donor, then why shouldn't those who are left require fulfilling those wishes? It's one thing if

you just died and your spouse wants to donate your organs that are fine. If you say you don't want that to happen, she shouldn't. You have stated you revoked your organ donor. That is my only concern.

Rep. Pietsch: A refusal is a simple signature.

Rep. Weisz: No a revocation is a simple signatures.

Rep. Price: C is any form of communication made by the individual.

Rep. Weisz: That is anything.

Rep. Price: That is a refusal.

Rep. Weisz: No read the definition of the refusal.

Rep. Price: Page 6 line 24 says an individual may refuse by a record signed by the person, or communication between some forms.

Rep. Weisz: Yes but that is not what the definition says. Refusal has to be on record.

Revocation doesn't.

Rep. Price: You are right.

Rep. Weisz: I don't want to muddy up the waters.

Rep. Kaldor: I'm wondering if this language doesn't also give the right let's say if you wanted to give a donation and your child made the decision that they don't want to. There is a way they are authorized to make that decision. I think it is on the bottom of page 9. I'm wondering if they have that language in place to allow for a revocation when a refusal hasn't been signed by a donor. In other words you decided you don't want to donate your organs but you forgot to sign the refusal. Now someone else is going to act on your behalf.

Rep. Weisz: So I die and my two boys are in charge. One of them revokes my gift. The way I also read out of the statute is beings is not a refusal, I am going to give. That is separate in the section. On page 7, that part refers strictly to the standpoint of refusal and revocation of the

donor. I don't think there is a problem on page 9. If I revoke myself I don't want my two sons to squabble and say that they are going to do it anyways.

Rep. Kaldor: So we should get the revocation in writing.

Rep. Weisz: Say you are on your deathbed and you say you revoke your own for whatever reason. I don't want my organs going elsewhere; it won't mean a thing because I won't have the time to actually do that.

Rep. Price: A revocation is to be used at the point that yes I am going to donate. Then maybe not. Someone else can make the decision and go through the order. That is what she indicated.

Rep. Weisz: There are too many definitions.

Rep. Schneider: I agree. You are not out of line by any means. But revocation and refusal are two different terms. It would be nice to have them spelled out. I think everything is protected as far as if you are in that situation and on your deathbed. You decide you don't want your organs donate.

Rep. Uglem: Do we need a change in definition. Refusal means a greater record. That doesn't meet the definition of a record. If it doesn't then why am I defining record in the first place? So are we defining record?

Rep. Weisz: Basically what we are saying is that you can give it to the adults and they put it in a written format.

Rep. Uglem: Is that just an error in the definition? Should that definition say 06 instead of 07? If that said 06 instead of 07 it would point to the definition.

Rep. Price: Right.

Rep. Weisz: No because beings the refusal is strictly addressed in that subsection, we are saying that the definition number is here. That definition of refusal is the one that applies. What it doesn't say is that it applies all the way through.

Rep. Kaldor: The definition is meant to apply in 2306-07. It isn't meant to apply there.

Rep. Price: The definition says the record created under, not applied to.

Rep. Weisz: That is what the point is; you would have to create a record to have a refusal. We can say that. It applies to the section where a record has to be created.

Rep. Uglem: I didn't come up with that.

Rep. Kaldor: I think you are right.

Rep. Price: There was no record created in 07.

Rep. Weisz: That is the point. It is not a refusal. It is created if it is a refusal. It is saying you revoke. The donor's revocation is not a refusal. A refusal goes back to its definition. What they are saying is that if you follow all the rules of revocation they don't apply unless you do what refusal does. I'm saying that either we need to make the definition of refusal more clear or figure something else out.

Rep. Price: The definition was not created in 07.

Rep. Uglem: There is no definition of organ.

Rep. Weisz: Also there is refusal for the records. Subsection C doesn't necessarily state that. The issue I brought up is how broad is it going to be in the end? For your spouse or someone to decide that.

Rep. Kaldor: That is why you need to do a refusal.

Rep. Weisz: Not everyone is going to understand a refusal. That is why I think it is going to have to be clear.

2007 HOUSE STANDING COMMITTEE MINUTES

Bill/Resolution No. SB 2163

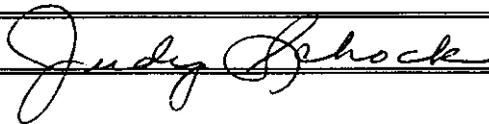
House Human Services Committee

Check here for Conference Committee

Hearing Date: March 19, 2007

Recorder Job Number: 5267

Committee Clerk Signature



Minutes:

Chairman Price: Take out SB 2163 for discussion and action. We have proposed amendments before us, and have been agreed to by Mr. Ward, and Judge Hagardy.

Chairman Price explains the bill and amendments to the students visiting our committee.

Representative Conrad: I move the amendments, seconded by **Representative Potter**. The verbal vote was unanimous. **Representative Conrad** moves a do pass as amended, seconded by **Representative Ugem**. The vote was 10 yeas, 0 nays, and 2 absent.

Representative Ugem will carry the bill to the floor.

PROPOSED AMENDMENTS TO ENGROSSED SENATE BILL NO. 2163

Page 4, Remove lines 1 through 3 and replace with: "25. 'Refusal' means an intention not to make an anatomical gift of a donor's body or part expressed in accordance with Section 23-06. 6 -06 which expressly states an intent to bar other persons from making an anatomical gift of an individual's body or part."

Page 19, line 1, after "recovery." insert "The procurement organization shall provide the coroner or medical examiner with all information it has which could relate to the cause or manner of the decedent's death."

Page 19, line 6, after "organ" insert "for transplantation"

Renumber accordingly

**House Amendments to Engrossed SB 2163 (70453.0201) - Human Services Committee
03/20/2007**

Page 4, line 1, replace "a record created under section 23-06.6-07" with "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"

**House Amendments to Engrossed SB 2163 (70453.0201) - Human Services Committee
03/20/2007**

Page 19, line 1, after the underscored period insert "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."

Page 19, line 6, after "organ" insert "for transplantation"

Renumber accordingly

Date: 3/19
Roll Call Vote #: 1

2007 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. "Click here to type Bill/Resolution No."

House HUMAN SERVICES SB-2163 Committee

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken Move Amendments

Motion Made By Rep. Conrad Seconded By Rep. Potter

Representatives	Yes	No	Representatives	Yes	No
Clara Sue Price – Chairman			Kari L Conrad		
Vonnie Pietsch – Vice Chairman			Lee Kaldor		
Chuck Damschen			Louise Potter		
Patrick R. Hatlestad			Jasper Schneider		
Curt Hofstad					
Todd Porter					
Gerry Uglem					
Robin Weisz					

Total (Yes) 11 "Click here to type Yes Vote" No 0 "Click here to type No Vote"

Absent 1

Floor Assignment Rep. _____

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

Date: 3/19
Roll Call Vote #: 2

2007 HOUSE STANDING COMMITTEE ROLL CALL VOTES
BILL/RESOLUTION NO. "Click here to type Bill/Resolution No."

House HUMAN SERVICES 2163 Committee

Check here for Conference Committee

Legislative Council Amendment Number _____

Action Taken As pass as amended

Motion Made By Rep. Conrad Seconded By Rep. Uglen

Representatives	Yes	No	Representatives	Yes	No
Clara Sue Price – Chairman	<u>L</u>		Kari L Conrad	<u>L</u>	
Vonnie Pietsch – Vice Chairman	<u>L</u>		Lee Kaldor	<u>L</u>	
Chuck Damschen	<u>L</u>		Louise Potter	<u>L</u>	
Patrick R. Hatlestad	<u>L</u>		Jasper Schneider		
Curt Hofstad	<u>L</u>				
Todd Porter	<u>L</u>				
Gerry Uglen	<u>L</u>				
Robin Weisz					

Total (Yes) 10 "Click here to type Yes Vote" No 0 "Click here to type No Vote"

Absent 2

Floor Assignment Rep. Uglen

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

REPORT OF STANDING COMMITTEE

SB 2163, as engrossed: Human Services Committee (Rep. Price, Chairman) recommends AMENDMENTS AS FOLLOWS and when so amended, recommends DO PASS (10 YEAS, 0 NAYS, 2 ABSENT AND NOT VOTING). Engrossed SB 2163 was placed on the Sixth order on the calendar.

Page 4, line 1, replace "a record created under section 23-06.6-07" with "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"

Page 19, line 1, after the underscored period insert "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."

Page 19, line 6, after "organ" insert "for transplantation"

Renumber accordingly

2007 TESTIMONY

SB 2163

Testimony in Support of
Senate Bill 2163
The Uniform Anatomical Gift Act
by District Judge Gail Hagerty
Senate Human Services Committee
January 17, 2007

Chair Lee, Members of the Committee:

I am Gail Hagerty, a district judge from Bismarck. I'm also a uniform law commissioner, and for the past two years, I've been involved in the drafting of a revised Uniform Anatomical Gift Act. It is that act which you have before you today.

In January of 2006, there were more than 92,000 people on the waiting list for organ transplantation, and the list is growing. The lack of organs results from a lack of organ donors.

The Revised Uniform Anatomical Gift Act was drafted to address, in part, the critical organ shortage by providing additional ways to make organ, eye and tissue donations. The Conference of Commissioners on Uniform State Laws adopted its first anatomical gift act in 1968. In 1987, the act was updated and revised. The legislation you have before you continues that process.

Since 1987, there have been improvements in technology and changes in federal law. This act will help North Dakota's law keep pace with those improvements and changes.

The new act honors the choice of an individual to be a donor or to decline to be a donor. It strengthens the language barring others from overriding a donor's decision. (Section 23-06.6-07)

It expands the list of those who may make gifts for another individual during that individual's lifetime, so that health care agents and, in some cases, parents or guardians may make gifts. (Section 23-06.6-03)

It empowers minors who are eligible to apply for a driver's license to designate an intention to be a donor. (Section 23-06.6-03)

It facilitates gifts from a deceased individual, who made no lifetime decision, by listing persons who can make gifts after death. (Section 23-06.6-08)

It permits an anatomical gift by any member of a class where there is more than one person

in a class. If there are several people in a class (for instance several children of a decedent), one of those people can make a gift, or if there is disagreement, a majority of the members of the class may make a gift. (Section 23-06.6-08)

It creates default rules for the interpretation of a document of gift which is not specific. (Section 23-06.6-10)

The legislation provides standards for donor registries. While it does not require creation of registries, it is intended to encourage registries and set minimum standards. (Section 23-06.6-19)

The legislation enables procurement organizations to gain access to documents of gifts in donor registries, medical records and the records of the state motor vehicle department. (Sections 23-06.6-19 and 23-06.6-13)

The new act also resolves the tension between a health-care directive requesting the withholding or withdrawal of life-support systems and making anatomical gifts by permitting measures necessary to ensure the medical suitability of organs for intended transplantation or therapy. (Section 23-06.6-13 and 23-06.6-20)

The act clarifies and expands the rules relating to cooperation and coordination between procurement organizations and coroners or medical examiners. (Section 23-06.6-21 and 23-06.6-22)

The act recognizes gifts made under the laws of other jurisdictions (Section 23-06.6-18) and updates the law to allow for electronic records and signatures. (Section 23-06.6-24)

The act was drafted over a period of two years with participation by a large number of individuals representing groups involved in anatomical gifts. It was read to the entire Conference of Commissioners on Uniform State Laws two times – line by line. It was amended and tweaked and reworked. It has received a great deal of study and I urge you to recommend that the act be passed.

Thank you.

January 17, 2007

North Dakota Legislation Session 2007

Senate Bill 2163

Testimony before the Human Services Committee

Susan Mau Larson

Public Affairs Director

LifeSource

Madam Chair. Committee Members. Good morning. My name is Susan Mau Larson. I am the director of Public Affairs for LifeSource. LifeSource is the non-profit organization dedicated to saving lives through organ and tissue donation in the Upper Midwest. Our role is to provide the bridge between the precious gifts of donation and those in need of a life-saving transplant. We manage all aspects of organ and tissue donation cases in North Dakota, South Dakota, Minnesota, and Western Wisconsin.

I am here today to offer our enthusiastic support for Senate Bill 2163, the revised Uniform Anatomical Gift Act. The UAGA is written to increase the number of lives saved through transplantation by providing uniformity in state laws, harmonizing law with current practice, and clarifying how individuals can document their wishes to donate and who may make gifts for a person who had died.

LifeSource's work of saving lives through donation and transplantation includes clinical management, professional education, donor family services and public education. Our

donation coordinators manage the clinical aspects of donation, including donor management, working collaboratively with the hospital and transplant centers, placing organs for transplant and coordinating recovery surgery. LifeSource hospital liaisons work with regional hospitals and transplant centers to build successful relationships with staff, including providing clinical education about donation and assisting them in complying with federal standards regarding donation and transplantation. The donor families that give such a wonderful and generous gift through donation are supported by a social worker and chaplain on staff with LifeSource; they provide grief support and resources, as well as manage annual recognition ceremonies. Finally, our Public Affairs department is responsible for educating the public about the continuing need for more people to say 'yes' to donation so that more lives can be saved through transplantation.

North Dakota has long been a leader and strong supporter of donation; 54% of North Dakota driver's and ID card holders have documented their wishes to donate. This compares to a national average of approximately 40%. Of those who die and can donate, 67% do – either they documented their wishes to donate and those wishes are fulfilled or the next-of-kin provides consent for donation. This compares to a national donation rate of 62%. These are wonderful numbers that are well above the national average. This State boasts a strong commitment to giving and a strong sense of community. However, if we are 67% why aren't we at 90% or 100%? When surveyed, 96% of Americans say they support donation. We know that when families are faced with a loss of a loved one and that loved one did not document their wishes to donate they will sometimes say no to

donation. This UAGA helps to ensure that every opportunity to learn about donation, document ones wishes, and have those wishes fulfilled is available.

A young woman at the age of 17 died recently in a car accident. This young woman had documented her wishes to donate. Her obituary read...Because Kelsey was so giving she had decided to be a donor and GIVE THE GIFT OF LIFE! At the funeral the minister and family recognized and honored the gift she had given to help others. In doing so, the family and friends were able to find some strength and some hope in their terrible tragedy. This is why donation is important for donor families.

It is our hope that the State of North Dakota will continue to demonstrate innovation and leadership in organ and tissue donation by being an early adopter of the revised Uniform Anatomical Gift Act.

We are pleased Senator Kilzer and other leaders have recognized the importance of this legislation and the State's role in continuing to advance donation in North Dakota. This legislation is being introduced in many states around the country. I am proud to say that North Dakota is one of the first, if not the first, to hold a hearing on this Bill.

On behalf of our staff at LifeSource I would like to personally thank Judge Gail Hagerty for her support and leadership of this important legislation. As a member of the NCCUSL drafting committee Judge Hagerty spent a considerable amount of time over the past two years carefully crafting the language in this bill, listening to key stakeholders, and

ensuring that the work of donation and transplantation moves forward in a manner which at every turn maintains the critical goal of supporting people and saving lives.

...Saving Lives... That is our goal.

As you read through this bill it is clear to see that a great deal goes into the work of saving lives. It involves a tremendous amount of science, care, humanity, skill, leadership, compassion. While it may seem complex at the end of the day it is quite simple.

Our work every day is focused on one thing... saving lives. Together, I truly believe we can prevent other people from suffering the same unnecessary fate that the Kerstings have experienced.

The decision you have before you today is made for the 95,000 people who are waiting for a life-saving transplant. The 95,000 people who, just like Alexa, need a second chance – a chance to celebrate another birthday, a chance to return to school or work, a chance to stand under the beautiful sky and take a breathe of fresh air.

If you pass Senate Bill 2163 you, Senators, are providing those 95,000 people with the hope that they will receive that second chance.

Thank you.

Alexa died waiting on the list for a lung transplant



Alexa's short life ended tragically early when she died at the age of 14 while waiting for a life-saving lung transplant. "She was a very talented little girl that we loved very much," says her father, Loren. "There's not a day that goes by that there's not an emptiness in the house. It's just not the same."

By the age of seven, Alexa was diagnosed with lung disease, and by the age of twelve she developed pulmonary hypertension, which triggered her placement on the transplant waiting list. For the seven months that Alexa was on the list, she was either at home or in the hospital, on oxygen 24 hours a day.

"Alexa couldn't do the things that most young girls are able to do, whether it was attending her first middle school dance, or riding bikes after school," says her mother, Monica. "All of her activities had to be quiet, like piano, art, or visiting with friends on the phone or at the house."

Alexa was a brave and courageous young girl who never gave up hope. She talked about all the things she was going to do when she received her transplant; dancing, earn her black belt in tae kwon do, learn to drive. "We were very, very hopeful," said Loren, "and we never gave that up."

Sadly, the call that would save her life never came. It's frustrating for Alexa's parents to know that the cure for their daughter existed, and all that it would have taken for her life to be saved is a generous grieving family, somewhere, who said 'yes' to donation.

"When you're a parent, you expect to be a parent for a long time," says Monica, "and it's hard to figure out a life without her."

*Visit DonateLifeMN.org today to document your wish to save lives through donation.
Questions? 888-5-DONATE or DonorRegistry@Life-Source.org*

LifeSource
Organ & Tissue Donation



LifeSource

Organ & Tissue Donation

FOR IMMEDIATE RELEASE

January 15, 2007

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www.organdonation.org

North Dakota Asked to Adopt Revised Uniform Anatomical Gift Act *New act intended to increase number of lives saved through transplantation*

Bismarck, ND (Jan. 15, 2007) — On January 17th at 10:00 a.m., the Human Services Committee, chaired by Senator Judy Lee of West Fargo, will be hearing proposed legislation to adopt a revised Uniform Anatomical Gift Act (UAGA) in North Dakota. The UAGA is the national model legislation that regulates donation of organs and tissues for transplant.

Each day, 17 people die simply because an organ they need is not available. Loren and Monica Kersting of West Fargo know this all too well. In July of 2004, their daughter, Alexa, died after waiting on a transplant list for seven months. Alexa was only 14 years old. The Kerstings will be among those testifying on behalf of this important legislation intended to positively advance organ and tissue donation in North Dakota. Senator Ralph Kilzer, Bismarck, is the prime sponsor of the act.

The Uniform Anatomical Gift Act was first drafted in 1968 and revised in 1987. North Dakota adopted the earlier acts. The latest revision of the act was drafted by the National Conference of Commissioners on State Laws to increase the number of lives saved through transplantation, provide uniformity in state laws and keep the law current with available technology and federal law. District Judge Gail Hagerty, Bismarck, was on the committee which drafted the new act.

The bill clarifies how individuals can make gifts before death and who may make gifts for a person who has died. In addition, the bill would allow 14 to 18-year-olds to mark "donor" on their driver's license with a parent's approval and provide guidelines for establishment of donor registries.

Organ and tissue donation is a critical health issue that hinges on the generosity of others to share life with those in need. Currently, there are over 94,000 people waiting for organ transplants and each day, 17 people die because the organ they need is not available. One donor can save or enhance up to 60 lives through gifts of organs and tissue. All North Dakotans are asked to take a moment on Wednesday in memory of Alexa and visit their local drivers' license station to add donor to their driver's license. Locations of the stations can be found online at www.dot.nd.gov/dlts.html.

Others expected to testify in support of the act include Susan Mau Larson, LifeSource, the non-profit organization dedicated to saving lives through organ and tissue donation in North Dakota.

###

LifeSource is the non-profit organization dedicated to saving lives through organ and tissue donation in the Upper Midwest. The LifeSource service area covers North Dakota, South Dakota, Minnesota and portions of western Wisconsin.

**DONOR DESIGNATION
IN NORTH DAKOTA**

Donor Designation on Driver's Licenses.....	261,891
State Population (Aug 2006).....	636,677
Percentage of State Population with Donor Designation	41%
License and ID Card Holders (Aug 2006).....	486,340
Percentage of Licensed Drivers with Donor Designation	54%
Donation Rate	67%

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A Donate Life Organization

LifeSource

LifeSource is the non-profit organization dedicated to saving lives through organ and tissue donation in the Upper Midwest. The LifeSource service area covers Minnesota, North Dakota, South Dakota and portions of western Wisconsin. LifeSource is accredited by the Association of Organ Procurement Organizations (AOPO), monitored by Medicare and the Food and Drug Administration (FDA), and each year goes through an independent financial audit.

Vision

We believe that life is a gift to share.

Mission

We pledge to provide the bridge between the loss of life and the gift of life through organ and tissue donation and transplantation.



Location

Headquartered in St. Paul, LifeSource has regional offices in Rochester, Minnesota; Fargo, North Dakota; and Sioux Falls, South Dakota.

Clinical Management

LifeSource manages all aspects of organ and tissue donation, from identifying potential donors to matching organs with those waiting for transplant, to coordinating clinical activities and arranging surgical recovery teams. LifeSource donation coordinators and tissue recovery coordinators link the stages of the donation and transplantation processes.

Communications

LifeSource actively promotes awareness and understanding about donation through communications activities, including professional education, media relations, community initiatives, volunteer services and donor family services.

Board of Directors

The LifeSource Board of Directors is comprised of individuals from transplant programs, as well as transplant recipients, members from donor families, and other community representatives.



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A Donate Life Organization

Questions and Answers on Organ and Tissue Donation

How serious is the organ shortage?

The need for organs continues to grow at an alarming rate and is truly a public health crisis. There are currently more than 90,000 men, women, and children in the United States waiting for a life-saving transplant. More than 2,300 of these individuals live in the Upper Midwest. Every 13 minutes another name is added to the national waiting list, and each day 17 people die while they wait for their transplant.

How do I become an organ and tissue donor?

Marking your intentions to become an organ and tissue donor on your driver's license or state ID card will ensure that your wishes are fulfilled. Talk with your family about your decision so they can be prepared to support and honor your wishes.

What if my driver's license isn't marked with a "yes"?

In the absence of known donor designation, LifeSource will seek authorization for donation from the next-of-kin. Therefore, it is extremely important that you share your wishes with your family as they can ensure that your wishes are fulfilled.

What can be donated?

Organs: Heart, lungs, kidneys, pancreas, liver and intestines.

Tissue: Corneas, skin, veins, tendons, bone, bone marrow, heart valves and connective tissue.

What are the benefits of organ and tissue donation?

Families who make the decision to extend the gift of life often find that donation helps them through their grieving process. Donation is something positive that can come from the death of a loved one. One person can save or enhance up to 60 lives through organ and tissue donation.

Should my age or health condition influence my decision to become an organ and tissue donor?

No. While medical history and age are factors, most people CAN donate. People with diabetes, hepatitis, and cancer sometimes CAN donate their organs. The only individuals who cannot donate are those who test positive for the HIV virus. Age criteria are evaluated individually.

What are the criteria for becoming an organ and tissue donor?

Organs and tissues can only be donated after death. Age and health criteria are evaluated on an individual basis at the time of death; everyone should consider themselves a potential organ and tissue donor.

Will my body look different if I donate my organs and tissues?

Donation is a surgical procedure. As in any other medical procedure, the body is treated with great respect and dignity.

Will my family have to pay for the cost of my organ and/or tissue donation?

There is no cost to the donor family for donation. All expenses related to organ and tissue donation are assumed by LifeSource and passed on to the transplant recipients and their health insurers.

Does my religion support organ and tissue donation?

Most major religions support organ and tissue donation as one of the highest forms of loving, giving and caring – the principles upon which all religions are based.

If I am a donor, will I be able to have a regular, open-casket funeral service?

Donation does not prevent an open-casket funeral service.

If I'm carrying a donor card, or if "Donor" is on my driver's license and I am admitted to a hospital, will they let me die so they can recover my organs?

No. The first responsibility of medical professionals is to save lives, and every effort will be made to save your life before donation is considered. Organ and tissue donation is offered as an option to your family only after all life-saving measures have failed and you have been declared legally dead.

Can organs and tissues be recovered prior to death?

No. Donation is only an option after death has been declared.

How are organs distributed to patients waiting for organ transplants?

Every person waiting for an organ transplant is registered with UNOS, the United Network for Organ Sharing. The organ procurement organization works with UNOS to fairly allocate organs based upon medical urgency, genetic matching and length of time waiting.

Is there a "black market" for organs in the United States?

No. It is illegal to buy or sell human organs and tissues in the United States (Anatomical Gift Act of 1968). In addition, every organ and tissue donation and transplant is reviewed by a national governing body. Strict regulations prevent any type of "black market" from existing in the United States

Do the rich and famous have a better chance of receiving a transplant?

Eligibility to receive an organ transplant is not determined by a person's financial status or celebrity. After a patient has been determined to be a medically-suitable candidate for an organ transplant, their name is added to the national computer waiting list. Organs are fairly allocated based upon medical criteria, genetic matching, and length of time on the waiting list.

Will the identity of the organ donor be revealed to the transplant recipient?

The identities of both the recipient and the donor family are confidential. The LifeSource coordinator sends a letter to the donor family informing them about the organ recipients such as their age and sex, and how their health has improved. Some donor families and recipients correspond anonymously. On occasion, when both sides wish to correspond directly or meet, LifeSource will help facilitate the communication or meeting.

Why should minorities be especially concerned?

Some diseases of the kidney, heart, lung, pancreas and liver are found more frequently in racial and ethnic minority populations. Transplantation between people who are strong genetic matches is generally more successful. Recipients have a better chance of finding a match from their same racial group. Approximately 50 percent of all people on the waiting list are minorities while only 25 percent of all donors are minorities.

Fast Facts about Organ Donation

Thousands of men, women, and children in the United States are waiting for organ transplants that could save their lives. Each year, approximately one-third of those people receive life-saving transplants and a hope for a renewed life because of the generosity of individuals who at a time of personal grief think of others in need. Despite this generosity, the need continues to grow. **Each day, 17 people die while waiting for a transplant. A new name is added to the transplant waiting list every 13 minutes.**

National Waiting List December 2006	
UNOS Data	
# of patient candidates on the National Waiting List	94,256
Kidney	69,604
Pancreas	1,776
Kidney-Pancreas	2,394
Liver	17,045
Heart	2,846
Heart-Lung	140
Lung	2,879
Intestine	237

Total may be less than the sum due to patients included in multiple categories

Regional Waiting List December 2006	
UNOS Data	
# of patient candidates on the Regional Waiting List	2,477
Kidney	1,508
Pancreas	185
Kidney-Pancreas	124
Liver	569
Heart	108
Heart-Lung	8
Lung	137
Intestine	3

National Statistics 2005	
UNOS Data	
# of deceased organ donors	7,594
# of living organ donors	6,898
# of organs transplanted	28,109
Kidney	16,477
Pancreas	540
Kidney-Pancreas	902
Liver	6,444
Heart	2,127
Heart-Lung	33
Lung	1,408
Intestine	178

Regional Statistics 2005	
LifeSource Data	
# of deceased organ donors	181
# of living organ donors	479
# of organs transplanted	607
Kidney	265
Pancreas	47
Liver	149
Heart	66
Lung	75
Intestine	5

Regional donor organs transplanted both locally and nationally

Patient Survival Rates One Year After Transplant	
UNOS Data	
Kidney	96%
Pancreas	95%
Liver	88%
Heart	86%
Heart-Lung	67%
Lung	79%

How Long Can Organs Be Preserved Before Transplant?	
Kidney	12-24 hrs
Pancreas	Up to 24 hrs
Liver	12-24 hrs
Heart	4-6 hrs
Heart-Lung	4-6 hrs
Lung	4-6 hrs
Intestine	Up to 24 hrs

The LifeSource region includes Minnesota, North Dakota, South Dakota, and portions of western Wisconsin.

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A Donate Life Organization

Uniform Anatomical Gift Act (UAGA)

The Uniform Anatomical Gift Act was carefully drafted with the goal of positively advancing donation and increasing the number of lives saved through transplantation.

The UAGA is the national model legislation that regulates donation of organs and tissues for transplant.

The UAGA was first drafted in 1968 and adopted by all states. It was revised in 1987 and adopted by 26 states including North Dakota.

The UAGA was drafted by the National Conference of Commissioners on Uniform State Laws (NCCUSL), a non-profit association comprised of commissioners from each state which works towards the goal of uniformity in state laws.

North Dakota is among the first states in the country to hear the revised UAGA in a legislative committee.

Adoption of the revised UAGA would achieve the following:

- Providing uniformity in laws among all states
- Harmonizing state law with current technology and practice
- Clarifying how individuals can document their wishes to donate and ensuring those wishes are fulfilled
- Clarifying the list of who may make gifts for a person who has died
- Allowing 14 to 18-year-olds to mark "donor" on their driver's license and donate with a parent's approval.

All North Dakotans are asked to take a moment on Wednesday in memory of Alexa and visit their local drivers' license station to add donor to their driver's license.

- Locations of the stations can be found online at www.dot.nd.gov/dlts.html.
- Indicating "donor" on a license or state ID card is authorization for donation and will ensure your wishes are fulfilled. Individuals are encouraged to share their wishes with their family.



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Hello, my name is Donna Gage. I am a registered nurse and work collaboratively with organ donation and Life Source, our regional organ procurement organization. My goal and purpose is to increase organ donation is multi fold, personally and professionally.

* a few years ago I had a niece at 22 years of age from North Dakota die from a stroke on Christmas day. She was able to donate all her organs. Today, I am here to honor her.

* a few years ago I had a brother -in-law from North Dakota who received a lung translant due to Cystic Fibrosis. Today, I am here to honor his donor who gave him the chance of a new life.

* But most of all I am here today as a professional nurse to assist donor families in making the final decision to donate their loved ones organs and give others a new gift of life. " What could be more rewarding?"

Everyday when I go to work, my goal is to optimize the best outcomes for patients and families with the ultimate goal for the patient to go home. But, when I can no longer do this and death becomes imminent my challenge is helping patients' families make the transition from curative to end of life decisions. Thus, providing adequate communication and support for patients' families who are considering organ donation is of utmost importance during the transition away from the goal of cure.

This is where our regional organ procurement organization, Life Source and hospitals have and must join in collaboration of increasing organ donation with the goal of "saving or enhancing thousands of lives a year by speading know best practices to achieve organ donation rates by a goal of 75%

or higher. I can make a difference, my fellow nurses, physicians, social workers, pastoral care, and hospital leadership can and must make a difference in this collaboration by achieving:

- * referral rates for donation by 100%
- * increasing our conversion rate to 75%
- * a timely notification rate to 100%
- * and having an appropriate requestor rate

In collaboration, I can become a donor "champion" in my institution. Help my colleagues understand the benefits of donation, including improved health for transplant recipients and comfort for grieving families of donors. Also, sign a donor card and tell your family about your decision to donate.

In collaboration, I advocate for my patients and their families. I honor my patients last wishes, including those related to donation.

In collaboration, Life Source and our hospitals now are working on successful donation systems that have protocols that personalize the approach to families of potential donors. This allows our nurses and health care team in working with Life Source staff to develop a sense of trust with each family and ensures the family has a positive experience with the donation process.

Significant improvement in organ donation rates must improve and are possible when hospitals and organ procurement organizations work together collaboratively to

redesign donation systems and implement evidence-based best practices.

Just yesterday, a family came back to visit our critical care unit after their son had died of a trauma. Organ donation had been requested by the family and performed. Hugs were given by all, but the final words of the father were, "his donation saved others lives and gave them a new beginning." What could be more rewarding then to give others,
"THE GIFT OF LIFE."

So sign a donor card and tell your family about your decision to donate.

Thank you.

**Testimony
Senate Bill 2163**

Senate Human Services Committee

January 17, 2007 10:00 a.m.

Good morning, Madam Chair and members of the Senate Human Services Committee. My name is Dr. Mary Ann Sens and I am a forensic pathologist. I am here today to testify in support of Senate Bill 2163 and also to highlight considerations of some aspects of SB2163 that are difficult in rural environments when interface with medical legal death investigation is needed.

I currently hold the position of Chair at the University of North Dakota's School of Medicine Department of Pathology. I also serve as County Coroner for Grand Forks County and am the Acting North Dakota State Forensic Examiner. I am a board member of the National Association of Medical Examiners and am on the Medical Advisory Board for Lifesource Organ and Tissue Procurement Agency.

Let me begin this morning by stating that I am a strong advocate of organ and tissue procurement. Throughout my twenty-plus years in forensic medicine I have never refused an organ procurement request. I have testified in criminal cases where the procurement of organs and tissues prior to the forensic autopsy was permitted. I have been responsible for transplant pathology for heart and kidneys recipients. In this capacity, I worked with patients needing and receiving critical organ donations. I fully understand the importance of utilizing human organs and tissue for implantation, especially in the pediatric patient, over artificial materials and devices.

I do, however, feel that it is necessary to understand that there are differences between organ procurement and tissue procurement; and how divergence of common goals between the coroner / medical examiner and the procurement agencies can occur, especially in rural settings. To this end, I will provide a background of the differences between organ and tissue procurement and the difficulties that may be encountered in rural settings.

Organ procurement: Organ procurement requires a donor on life support systems to maintain heart and lung functions. Usually, the individual meets the criteria of brain death. In some circumstances, "beating heart donors" are also organ donors. In ALL these cases, the patient is hospitalized, on artificial life support systems and frequently has had several medical and surgical interventions in an attempt to save life. Brain death criteria take several hours to confirm and often a day or more from the initial incident and the pronouncement of death, after which life support systems artificially

support heart and lung physiologic functions until organ donation is accomplished. The time delay, initial assessment, treatment and interventions until donation is accomplished, or even requested, invariably reduce the ability to obtain a great deal of forensic evidence. Many standards of death investigation, such as petechial hemorrhages, lividity and rigidity patterns, trace evidence on the body, etc. are simply gone or not applicable. This is how it should be – we attempt to preserve life whenever possible and forensic evidence is secondary. Relevant to this legislation, at the time of organ donation, there often is little forensic evidence to collect and maintain, or it is located (such as a bullet) in an area far away from the donated organs. The very fact that organs are donated for transplantation and continue to work (even in adverse conditions) in another human, whose life is often saved by the transplant, negates any attempt to ascribe the cause or contributing factors of death to the donated organs. Thus, in my experience, I have never found cause to deny organ procurement, even in homicide cases.

Tissue procurement: Tissue procurement (bones, skin, heart valves, joints, vessels and eyes) primarily provides life enhancing therapies. These, while very important, generally do not have the critical urgency of organ transplantation. In sharp contrast to organ procurement, some tissues are actually harvested in excess of what the state and country need and are exported outside of the US. Donors who are found deceased may become tissue donors. The need for artificial life support is not present. Salient to this legislation, most instances of tissue donation (unless the donor is also an organ donor) occur when the person is found deceased. Many of these deaths fall under coroner jurisdiction. All the information relevant to accurate medical-legal death investigation must be gathered and assessed. This includes position, lividity and rigidity patterns, petechia, trace evidence on body and clothing and other critical components of death investigation. Many findings, such as petechia in eyes, are absolutely critical for distinguishing subtle potential homicide deaths (such as smothering) from natural deaths. Any legislation must preserve this critical component of medical legal death investigation. Unlike organ donors, this information may be irretrievably lost if careful attention to details of tissue procurement authorization, donation and evaluation are not followed. Individuals who assess and document these key medical-legal findings must be trained, reviewed, capable and willing to testify and be accepted in the ND court system relative to their involvement in the death investigation. This task is much more complex in a rural environment. This difficulty is heightened by the current death investigation system in North Dakota. I will address why.

Challenges in rural settings. The timing needed for procurement creates challenges for all interfaces with coroner/medical examiner/forensic examiner systems. These are increased significantly in rural settings due to several factors not usually problematic in large population bases and small geographic areas.

1. Distance / Weather: Deaths occur in all communities, often at considerable distance from both the forensic examiners and procurement centers. Most donations will involve transport to a major medical center, thus limiting local investigation. In many rural communities, there are no mechanisms for even temperature controlled storage of deceased remains that would allow both conditions for successful procurement and a window of opportunity for the needed local investigation.
2. Part-time coroners: To my knowledge, there are no full-time coroners in ND, and none with the usual 24/7/365 staffing common in larger localities. When a reportable death occurs, the coroner is called, but usually has patients in his/her office, hospital or in the case of our frontier counties, other job responsibilities. Coroners are usually a distance away from where the death occurred, creating time delays in investigation. When coupled with the need to conduct minimal local investigation and forensic evidence, timing for successful donation and investigation often becomes an issue.
3. Training: Most ND coroners do not have formal death investigation training. The interface with the state forensic examiner has assisted greatly, but more training and review opportunities are greatly needed.

National Positions:

It is the position of the National Association of Medical Examiners (NAME) to facilitate all organ donations. We understand both the life saving need for organs and bear witness to the comfort this brings donor families in a time of sorrow and loss. NAME initiated a campaign to increase organ procurement – “Every organ, every time” several years ago targeting increased cooperation with procurement agencies. We are committed to honor the final wishes of the person that makes a donation. In this regard, there are many aspects of this proposed legislation that are needed and productive. Despite strong support for procurement, the membership and the Board of Directors of NAME voted overwhelmingly NOT to support this proposed legislation. The objections of NAME revolve around (1) the lack of delineation of organ and tissue procurement, (2) the lack of delineation between live saving transplantation and use of organs and tissues for training and research, (3) statutory conflicts with some medical examiners systems and current state law in some locations; (4) “onerous” and extremely difficult mechanism proposed for denying procurement, which requires the coroner or medical examiner to personally attend the procurement to disallow organ and tissue use in a given case. These are serious objections, largely revolving around the lack of delineation between organs, tissue, life-saving transplants, research and training uses. There is a lack of appreciation for the difficulty, particularly in rural environments, of accomplishing the dual task of

facilitating organ and tissue use and providing basic medical-legal investigation of a death.

Local Interpretation and Issues:

I share these concerns of NAME and bring additional insight of the challenges in rural settings, heightened by my recent role as Acting State Medical Examiner, of some of the difficulties in this legislation as proposed. Yet I strongly support the goals of the legislation and many of the needed elements in this important area.

I believe with some minor modification, North Dakota can exert national leadership in this important area and set a standard for successful organ and tissue procurement in a rural setting – the most challenging of all procurement settings. I have outlined considerations for the committee to address in deliberations and modifications of this bill to best serve rural populations. We can honor the work Judge Hagerty in crafting this important legislation. Finally, I close with a few additional considerations the Human Services Committee to assure not only increased organ and tissue donation, but increased safety of organs/ tissues and improvements in ND death investigation.

Proposal:

- 1) Revise the denial by a medical examiner, coroner, (state forensic examiner) criteria to ORGANS – not tissue. This was recommended as an amendment and passed. Although the requirement for personal attendance to deny procurement is still so difficult it is for all practical purposes unachievable in North Dakota, in reality, my experience has been that a basis for denial of ORGANS for transplantation (not research or education) is vanishingly rare. This will assist in facilitating life-saving organs for transplantation and reinforce working relationships between organ procurement agencies and various medical forensic entities (coroners, state forensic examiners, medical examiners, forensic pathologists) involved in death investigation.
- 2) Study protocols and policy development for ND. Death investigation in North Dakota has room for improvement in order to provide an acceptable standard of service to the citizens, families and various state agencies. These considerations are involved but tangential to this legislation and are the subject of a study committee of the Department of Health, State of North Dakota. Facilitating tissue and organ procurement is an agenda item for this committee as it reviews all aspects of death investigation and services for North Dakota.
- 3) Establish criteria for individuals involved in organ and tissue retrieval. Although this bill contains some language regarding responsibilities of OPA for documentation and potential testimony in deaths that fall under coroner – medical examiner jurisdiction, the responsibility this entails should be clear to

all parties, either in the written guidelines between agencies or by formal statute. If organ and tissue agencies are going to utilize coroner / medical examiner / forensic examiner cases, the individuals involved in recovery must bear the same responsibility for those aspects of death evaluation and documentation that are potentially altered during procurement as others responsible for medical-legal death investigation. Individuals must have training, expertise and be willing to provide court testimony without compromise of the case in addition to reporting findings to the responsible medical examiner. On cases involving coroner / forensic examiner jurisdiction, particularly those with known or potential homicidal deaths, this will likely limit the number of individuals participating in the recovery and may likely require those who are not physicians to successfully complete death investigation training (such as Certification by American Board of Medicolegal Death Investigation) for harvesting of tissue. Physicians involved in harvesting should have training and review of written findings relevant to trauma medical legal documentation for involvement in tissue donation from deaths likely to result in court action. In the court system and elsewhere, a case is only as strong as the weakest link. On cases involving potential court action, ALL individuals providing death investigation and assessment, be they technicians obtaining donated tissue or forensic pathologists performing an autopsy, must be acceptable and willing to provide expert testimony relevant to their participation in the investigation.

- 4) Engage local resources for notification. Co-sharing responsibility of OPA notification would be a great assistance to local coroners, who often are balancing other responsibilities of the death and jobs. Simply having local medical facilities notify and provide basic information to OPA would be of great assistance to coroners. Although laws now require hospitals to notify procurement officials for deaths that occur in their facility, this is not required, and often not done, on individuals who arrive at a medical facility after death has occurred. Alternatively, as potential revisions to death investigation occur as considered by the ND DOH committee reviewing this system, increased responsibilities by the State Forensic system may be formulated.
- 5) The language of the legislation should be uniform and consistent with ND Century Code, with the use of Coroner, State Forensic Examiner and/or Medical Examiner.

Additional considerations for the committee and legislature:

Safety of organ and tissue procurement: Although this legislation does not address safety of organ and tissue procurement, North Dakota has an opportunity to insure increased safety of organs and tissues for transplantation and therapy. As the donor pool increases in age allowance, the potential for undetected disease, particularly cancer, increases. Currently, my rate of undetected cancer at autopsy is 7%. Nationally, some practices are higher, some lower. Degenerative and infectious disease, particularly of the brain, may not be detectable without autopsies. Requiring autopsies on organ and many tissue donors would increase the safety of the donor pool, as well as providing health information to families and occasionally critical information (like Rabies detection) for public health officials. I have more information if desired on this subject.

I thank you for consideration of these issues.

Mary Ann Sens, MD, PhD

NDLA, S HMS

From: Lee, Judy E.
Sent: Saturday, January 27, 2007 6:31 PM
To: NDLA, S HMS (shms@nd.gov)
Subject: FW: Mary Ann Sens SB2163

Attachments: Testimony SB 2163.pdf



Testimony SB
2163.pdf (23 KB)

Mary - Please put this testimony in our books.

-----Original Message-----

From: Mary Ann Sens [mailto:msens@medicine.nodak.edu]
Sent: Saturday, January 27, 2007 5:04 PM
To: Lee, Judy E.; GHagerty@endcourts.gov; blevi@NDMED.COM; Kilzer, Ralph L.; Erbele, Robert S.; Dever, Dick D.; Heckaman, Joan M.; Pomeroy, Jim R.; Warner, John M.
Cc: Lahren, Craig H.; Smith, Arvy J.
Subject: Mary Ann Sens SB2163

Here is a copy of my testimony for SB 2163, Uniform Anatomic Gift Acts. I realize you have acted on this important bill and GREATLY appreciate the amendments as passed. I apologize for both the lack of written testimony at the time and the delay in getting this done. It has been very difficult working in both Bismarck and Grand Forks.

I hope you will find this information useful in continued progress of this bill. Please email me directly if there are any additional questions or elaboration of the points in this legislation that is needed.

Again, THANK YOU for your kind attention and consideration of this bill and amendments to assure this will work for the State.

Mary Ann Sens

--
Mary Ann Sens, MD PhD
Professor and Chair of Pathology
University of North Dakota School of Medicine and Health Sciences

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Testimony in Support of
Senate Bill 2163
The Uniform Anatomical Gift Act
by District Judge Gail Hagerty
House Human Services Committee
March 7, 2007

Chair Price, Members of the Committee:

I am Gail Hagerty, a district judge from Bismarck. I'm also a uniform law commissioner, and for the past two years, I've been involved in the drafting of a revised Uniform Anatomical Gift Act. It is that act which you have before you today.

In January of 2006, there were more than 92,000 people on the waiting list for organ transplantation, and the list is growing. The lack of organs results from a lack of organ donors.

The Revised Uniform Anatomical Gift Act was drafted to address, in part, the critical organ shortage by providing additional ways to make organ, eye and tissue donations. The Conference of Commissioners on Uniform State Laws adopted its first anatomical gift act in 1968. In 1987, the act was updated and revised. The legislation you have before you continues that process.

Since 1987, there have been improvements in technology and changes in federal law. This act will help North Dakota's law keep pace with those improvements and changes.

The new act honors the choice of an individual to be a donor or to decline to be a donor. It strengthens the language barring others from overriding a donor's decision. (Section 23-06.6-07)

It expands the list of those who may make gifts for another individual during that individual's lifetime, so that health care agents and, in some cases, parents or guardians may make gifts. (Section 23-06.6-03)

It empowers minors who are eligible to apply for a driver's license to designate an intention to be a donor. (Section 23-06.6-03)

It facilitates gifts from a deceased individual, who made no lifetime decision, by listing persons who can make gifts after death. (Section 23-06.6-08)

It permits an anatomical gift by any member of a class where there is more than one person

in a class. If there are several people in a class (for instance several children of a decedent), one of those people can make a gift, or if there is disagreement, a majority of the members of the class may make a gift. (Section 23-06.6-08)

It creates default rules for the interpretation of a document of gift which is not specific. (Section 23-06.6-10)

The legislation provides standards for donor registries. While it does not require creation of registries, it is intended to encourage registries and set minimum standards. (Section 23-06.6-19)

The legislation enables procurement organizations to gain access to documents of gifts in donor registries, medical records and the records of the state motor vehicle department. (Sections 23-06.6-19 and 23-06.6-13)

The new act also resolves the tension between a health-care directive requesting the withholding or withdrawal of life-support systems and making anatomical gifts by permitting measures necessary to ensure the medical suitability of organs for intended transplantation or therapy. (Section 23-06.6-13 and 23-06.6-20)

The act clarifies and expands the rules relating to cooperation and coordination between procurement organizations and coroners or medical examiners. (Section 23-06.6-21 and 23-06.6-22)

The act recognizes gifts made under the laws of other jurisdictions (Section 23-06.6-18) and updates the law to allow for electronic records and signatures. (Section 23-06.6-24)

The act was drafted over a period of two years with participation by a large number of individuals representing groups involved in anatomical gifts. It was read to the entire Conference of Commissioners on Uniform State Laws two times – line by line. It was amended and tweaked and reworked. It has received a great deal of study and I urge you to recommend that the act be passed.

Thank you.

Wednesday, March 7, 2007

TESTIMONY IN SUPPORT OF SB 2163

Chairwoman Price and Members of the House Human Services Committee:

My name is Pat Ward. I am with the Bismarck law firm of Zuger Kirmis & Smith. I represent Life Source in support of SB 2163.

I am here to introduce you to Susan Mau Larson who is Director of Public Affairs for Life Source. She will explain to you the role that Life Source plays in upper midwest organ procurement and why we support the newest version of the Uniform Anatomical Gift Act contained within SB 2163.

The Revised UAGA has the endorsement of the American Academy of Ophthalmology, American Association of Tissue Banks, American Bar Association, American Medical Association, American Society of Cataract and Refractive Surgery, AOPO, Eye Bank Association of America, National Kidney Foundation, The Cornea Society, and UNOS.

Before I introduce Susan, I would just like to tell one feel good story regarding organ donations from my family.

My uncle Fay, a farmer in northern Minnesota near Bemidji, is probably out checking on his cattle this morning and getting ready for calving. He's probably got country music on the radio or he's whistling or singing a cowboy song. He is definitely driving a Ford pickup. He's the guy that taught me how to milk a cow and how to drive a tractor.

None of this is remarkable for most farmers, but it is for my uncle Fay. About 15 years ago he was told that his heart was failing and that he had 6 months to a year to live if he was lucky. He was luckier than that, he got on the list for organ donation and even though he had priority status due to the severity of his condition, he had to wait more than a year. He was getting weaker and was giving up hope. He was only in his 50's.

One day he got the phone call he was waiting for. A heart had been located in the Minneapolis area that was a probable match. A young man had been killed in a motorcycle accident and the family donated the organ. Uncle Fay got his new heart. He has lived all these years happily going about the business of raising his beef cattle and singing his cowboy songs. His 8 children, and I don't know how many grandchildren, are happy to have him around.

You will also hear the sad stories today about people who have had to wait too long and didn't get an organ they needed in time.

I urge you to recommend a do pass on SB 2163 so that more lives can be saved.

Thank you for your attention and I will try to answer any questions if I can.

March 7, 2007

North Dakota Legislation Session 2007

Senate Bill 2163

Testimony before the House Health and Human Services Committee

Madam Chair. Committee Members. Good morning. My name is Susan Mau Larson. I am the director of Public Affairs for LifeSource. LifeSource is a non-profit organization dedicated to saving lives through organ and tissue donation in the Upper Midwest. Our role is to provide the bridge between the precious gifts of donation and those in need of a life-saving transplant. We manage all aspects of organ and tissue donation cases in North Dakota, South Dakota, Minnesota, and Western Wisconsin.

I am here today to offer our enthusiastic support for Senate Bill 2163, the revised Uniform Anatomical Gift Act. The UAGA is written to increase the number of lives saved through transplantation by providing uniformity in state laws, harmonizing law with current practice, and clarifying how individuals can document their wishes to donate and who may make gifts for a person who had died.

North Dakota has long been a leader and strong supporter of donation. 54% of the driver's and ID card holders have documented their wishes to donate. This compares to a national average of somewhere around 40%. Of those who die and can donate, 67% do – either they documented their wishes to donate and those wishes are fulfilled or the next-of-kin provides consent for donation. This compares to a national donation rate of 62%. These are great numbers and well above the national average. This State boasts a strong commitment to giving and a strong sense of community. However, if we are 67% why aren't we at 90% or 100%. When surveyed, 96% of Americans say they support donation. We know that when families are faced with a loss of a loved one and that loved one did not document their wishes to donate they will sometimes say no to donation. This UAGA helps to ensure that every opportunity to learn about donation, document one's wishes, and have those wishes fulfilled is available.

For a number of years we have been partnering with the State of North Dakota Department of Transportation under the leadership of Marshal Lembke. The State ensures that information about donation is available in all the driver's license stations. When there is a potential donor from North Dakota we are able to call State Patrol 24/7 and they will tell us if the person had donor designated on their driver's license. This ensures we are able to honor and fulfill those wishes to donate. To that end, I encourage all of you who don't have donor on their license to walk across the street after this meeting and the staff in the station will change that license for you.

It is our hope that the State of North Dakota will continue to demonstrate innovation and leadership in organ and tissue donation by being an early adopter of the revised Uniform Anatomical Gift Act.

We are pleased Representative Carlisle and other leaders have recognized the importance of this legislation and the State's role in continuing to advance donation in North Dakota. On behalf of our staff and Board of Directors at LifeSource I would like to personally thank Judge Gail Hagerty for her support and leadership of this important legislation. As a member of the NCCUSL drafting committee Judge Hagerty spent a considerable amount of time over the past two years carefully crafting the language in this bill, listening to key stakeholders, and ensuring that the work of donation and transplantation moves forward in a manner which at every turn maintains the critical goal of supporting people and saving lives.

...Saving Lives... That is our goal.

As you read through this bill it is clear to see that a great deal goes into the work of saving lives. It involves a tremendous amount of science, care, humanity, skill, leadership, compassion. While it may seem complex at the end of the day it is quite simple.

Our work every day is focused on one thing... saving lives. Because the waiting list for transplant is so long that doesn't always happen. Alexa Kersting was a 14-year-old girl from West Fargo who desperately needed a lung transplant and died 2 years ago because she didn't receive the gift of transplantation. I am going to hand out a flier which has background information on Alexa's sad story along with a link to our newly launched website which has information about donation and how North Dakotans can document their wishes to donate.

The outcome for Alexa and her family was devastating. Together, I truly believe we can prevent other people from suffering that same unnecessary fate.

The decision you have before you today is made for the 95,000 people who are waiting for a life-saving transplant. The 95,000 people who, just like Alexa, need a second chance – a chance to celebrate another birthday, a chance to return to school or work, a chance to stand under the beautiful sky and take a breathe of fresh air.

If you pass Senate Bill 2163 you, Senators, are providing those 95,000 people with the hope that they will receive that second chance.

Thank you.

Testimony

Senate Bill 2163

House Human Services Committee

March 7, 2007; 10:30 a.m.

Good morning, Madam Chair and members of the House Human Services Committee. My name is Dr. Mary Ann Sens, and I am the acting state forensic examiner for the North Dakota Department of Health. I am here today to provide information about Senate Bill 2163.

In addition to serving as the acting state forensic examiner, I am also the chair of pathology at the University of North Dakota School of Medicine and Health Sciences and the Grand Forks County coroner. I have an active, National Institutes of Health funded cancer research program and am active in several national pathology organizations, including serving on the Board of Directors of the National Association of Medical Examiners, the nation's leading professional organization representing the medicolegal death investigation community.

I am also a strong proponent of organ and tissue transplantation. Throughout my career of more than 20 years, I have never denied an organ procurement request. I have rarely denied or limited tissue procurement and most of those instances have been for reasons my testimony will make clear. I have worked as a transplant (heart and kidney) pathologist and know the importance of life-saving transplants for patients and families. As a forensic pathologist, I have seen the comfort these transplants provide to donor families in a traumatic time of profound loss. Thus I can speak with authority on both the complex emotional issues surrounding organ procurement and the difficulties of implementing this legislation.

Attached to my testimony is a letter from the National Association of Medical Examiners (NAME) stating its support of organ and tissue procurement, as well as its concerns about the Revised Uniform Anatomical Gift Act of 2006. NAME and the Uniform Anatomical Gift Act (UAGA) drafting committee have developed a "compromise draft," which I can provide to you if the committee is interested.

My testimony today will focus on the key features of this bill that affect rural populations and North Dakota.

- 1) This legislation changes all existing responsibilities for death investigation. As drafted, it revokes the historic responsibility of the coroner/medical examiner to manage medicolegal death investigation and gives the wishes of the organ procurement agency and the decedent equal or greater priority. In the bill, the sole mechanism for denial of organs and tissue, for any reason, is for the coroner/medical examiner to attend recovery procedure, object to procurement,

then to write objections in the record. The attendance requirement at recovery will not work in rural environments. The amendment passed by the North Dakota Senate that restricted this requirement to organ procurement is a great improvement. However, I would strongly recommend that this be clarified as "organs for transplantation," and exclude organs for research or educational purposes.

- 2) I recommend that the process of objecting to the use of organs be made feasible for rural practices. Coroners cannot, nor is it medically sound for them to, attend organ procurement to object to recovery of tissue relevant to medicolegal death investigation. I propose that a written statement from the coroner or forensic pathologist indicating reasons for denial at the time be accepted instead. This statement will be reviewed by peer review panel of forensic pathologists from the region in an effort to improve practice or confirm the denial. Such a panel exists with Lifesource. I am a member of this advisory committee and we routinely discuss such denials. Similar panels are used throughout many aspects of medical practice for physician performance and judgment issues. Mandatory attendance, often at distant medical centers, by part-time coroners and state examiners is not feasible in rural environments.
- 3) Tissue procurement and notification must remain within the domain of county coroners/state forensic examiners. If the investigation of a death has the potential to end up in court, evidence must be collected in a manner to preserve court proceedings, and the body must be examined for subtle findings. This evidence potentially is lost with procurement of tissues. It is imperative that the medicolegal process maintain integrity.
- 4) Having every coroner notify the organ procurement agency of every death will not work in the current North Dakota system. The state has no fulltime coroners; in fact, the state has limited central oversight of the entire system. Notification of agencies takes time – a lot of time based on current experience. Most deaths occur at home. Are we not to release a body to a funeral home until we contact the organ procurement agency? The draft version of UAGA would work in large metropolitan areas where teams of death investigators respond to every scene and pick up bodies for central office examination. It will not work in rural communities with part-time coroners, as well as geographic and weather barriers to medical centers where tissue donation can be accomplished. We can improve tissue referral and donation rates, and I am committed to doing so, but the protocols for North Dakota must be different than those for a major metropolitan area.
- 5) Tissue and organ procurement for research and education – that is, when organs will not be used for life-saving transplants and therapy – must not interfere in any way with medicolegal death investigation.

- 6) Although there certainly are altruistic aims with tissue procurement, there are also financial ones. Many tissues are actually in excess of what is needed in the region and this country and are exported to other nations. We cannot compromise medical legal death investigation here to financially benefit the organ procurement agency and send organs overseas. I can provide additional information about this subject if the committee is interested.
- 7) The language of the legislation should be uniform and consistent with North Dakota Century Code, with the use of the terms coroner, state forensic examiner and/or medical examiner.

Although this legislation does not address the safety of organs and tissues, North Dakota has an opportunity to ensure increased safety of organs and tissues for transplantation and therapy. As the donor pool increases in age allowance, the potential for undetected disease, particularly cancer, increases. Currently, my rate of undetected cancer at autopsy is 7 percent. Degenerative and infectious disease, particularly of the brain, may not be detectable without autopsies. Requiring autopsies on organ and many tissue donors would increase the safety of the donor pool, and would provide health information to families and occasionally critical information (like rabies detection) for public health officials.

In conclusion, I strongly support organ and tissue donation. I also support many aspects of this legislation. But the interface required with coroners and medical examiners will not work in rural environments. I strongly request that this bill be modified to account for the reality of rural practice.

This concludes my testimony. I am happy to answer any questions you may have.

The National Association of Medical Examiners®

430 Pryor St SW, Atlanta, GA 30312
404-730-4781



DATE: February 28, 2007

TO:

FROM: The National Association of Medical Examiners (NAME)

RE: Revised Uniform Anatomical Gift Act (UAGA)

The National Association of Medical Examiners (NAME) is the nation's leading professional organization representing the medicolegal death investigation community, including forensic pathologists, medical examiners and coroners. The forensic pathology community is unique in that we are a profession that interacts with both the medical and legal environments on a daily basis. We are uniquely qualified to understand and make critical decisions regarding issues related to medical as well as forensic concerns.

The Revised Uniform Anatomical Gift Act (UAGA) was recently sent to your state for consideration to implement through legislative action. It is particularly disturbing to our organization that a significant portion of the drafting process of the UAGA occurred without any consultation with the medical examiner community. A representative of NAME attended the final meeting of the drafting committee, with **no significant input** into the document. Despite the fact that the Revised UAGA twice lists NAME as an organization that approved of and was actively involved in the development of the document, the document was finalized prior to being seen, critiqued, or endorsed by the National Association of Medical Examiners. This letter serves to notify you of this fact, and to inform you that, at our organization's annual meeting in the fall of 2006, the NAME Board of Directors issued the following statement regarding the Revised UAGA:

The National Association of Medical Examiners wholeheartedly supports and encourages organ and tissue donation. However, NAME cannot endorse the Revised Uniform Anatomical Gift Act (2006) in its present form for the following reasons: 1. The stated mandate in the act frequently contradicts the existing statutory mandate of the Medical Examiner/Coroner within particular jurisdictions. 2. The act as written does not distinguish recovery for life-saving transplant from recovery for research and education. 3. The act as written does not distinguish between organs and tissues. 4. The procedure for legitimate denial is onerous and unreasonable.

The National Association of Medical Examiners has been and continues to be a strong supporter of organ and tissue donation. At the same time, our organization must remain a strong advocate for our members and their responsibilities to protect the public's health and safety. This is particularly true when legal and evidentiary issues related to a patient's death require a forensic pathologist to make critical decisions regarding organ and tissue donation in order to fulfill their mandates to determine the cause of death and to preserve and collect evidence.

The Revised Uniform Anatomical Gift Act that has been presented to you for consideration is a document that ignores and/or dismisses important legal forensic issues that are already mandated by law in many jurisdictions. We implore you to contact the National Association of Medical Examiners and your local medical examiner/forensic pathologist before acting on this piece of legislation.

Thank you for your serious consideration!

Sincerely,

Joseph A. Prahlow, MD
President, National Association of Medical Examiners

March 7, 2007

North Dakota Legislation Session 2007

Senate Bill 2163

Testimony before the House Health and Human Services Committee

Dear House Committee Members:

I want to tell you how important it is for you to pass on the Anatomical Gift Act that is before you today. In July of 2004 our daughter, Alexa died at the age of 14 while waiting for a lung transplant. She was number one on the list in our Region for 7 months, but no match was found. We never imagined that we would ever run out of time. We had the Hope that someone would turn a tragedy into a miracle and give Alexa a second chance at life. Our lives have been changed forever and we will always wonder why she didn't receive her transplant. We need to end the tragedy of people dieing on the waiting list, and passing this bill will get us one-step closer. Monica and I have worked hard, to do everything we can, to bring about awareness of this problem, and will continue to do so. We have traveled the US sharing our story of Alexa in the hopes of ending this loss of lives. It is now our turn, as well as yours, to do something for the people of North Dakota.

A recently formed ND committee is working hard to make a difference for all of those waiting for a transplant in our region. We are excited to see that this Act addresses the need of young drivers between the ages of 14 -18 to be able to voice their wishes, with parents still making the final decision. You too can make a difference by giving Hope to those 90,000 waiting on the list by passing this Bill. Through the strength we feel from Alexa, Monica and I will work endlessly to keep the Hope alive for those just like her waiting for a transplant and a second chance at life. We need your Help and support.

Thank you on behave of all those Waiting and Hoping!

Loren Kersting

NDLA, S HMS

From: Lee, Judy E.
Sent: Wednesday, March 28, 2007 12:45 PM
To: Dever, Dick D.; Erbele, Robert S.; Warner, John M.; Heckaman, Joan M.; Pomeroy, Jim R.; NDLA, S HMS
Subject: FW: SB 2163

Friends -

Here is information about 2163. I think I favor concurring, if it's acceptable to everyone.
Mary - Please include this in the notes for 2163.

From: Susan Mau Larson [mailto:smlarson@life-source.org]
Sent: Wednesday, March 28, 2007 12:41 PM
To: Lee, Judy E.
Cc: Patrick Ward; Hagerty, Gail
Subject: RE: SB 2163

Senator Lee,

I am happy to provide additional comments. Below are the amendments along with brief comments as to why LifeSource supports these. Please let me know if you have additional questions.

Page 4, line 1, replace "a record created under section 23-06.6-07" with "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"

There was concern that the definition of "record" was not consistent with Section 23-06.6-06 so "record" was changed to "intention" to provide clarity around how an individual would express a refusal to donate.²

Page 19, line 1, after the underscored period insert "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."

This language was suggested by the National Association of Medical Examiners. This is information that LifeSource provides the coroner/medical examiner in current practice and having it in statute would ensure that all procurement organizations follow similar practice.

Page 19, line 6, after "organ" insert "for transplantation"

This section puts responsibility on the medical examiner to attend an organ recovery in person if they wish to deny recovery. Adding the words "for transplantation" means they would only have to attend the recovery if the organs were intended for transplant and not for research. It is important that Medical Examiners work towards zero denial of donation for transplantation, but this same burden is not necessary for organs for research.

Susan Mau Larson
Director, Public Affairs
LifeSource

3/29/2007

651-603-7852

From: Lee, Judy E. [mailto:jlee@nd.gov]
Sent: Wednesday, March 28, 2007 12:26 PM
To: Susan Mau Larson
Subject: RE: SB 2163

Would you like to make a comment or two on the purpose of the amendments, for the benefit of our committee members?

From: Susan Mau Larson [mailto:smlarson@life-source.org]
Sent: Wednesday, March 28, 2007 11:27 AM
To: Lee, Judy E.
Cc: Patrick Ward; Hagerty, Gail
Subject: SB 2163

Senator Lee,

As you may be aware, yesterday the North Dakota House passed Senate Bill 2163 as amended by a vote of 93-0. I wanted to let you know that LifeSource is supportive of the amendments and recommend the Senate concur.

Thank you.

Susan Mau Larson
Director, Public Affairs
LifeSource
651-603-7852

3/29/2007