

ALASKA STATE LEGISLATURE
SENATE HEALTH, EDUCATION AND SOCIAL SERVICES STANDING COMMITTEE

April 7, 2004

5:45 p.m.

TAPE (S) 04 - 20

MEMBERS PRESENT

Senator Fred Dyson, Chair
Senator Gary Wilken
Senator Bettye Davis
Senator Gretchen Guess

MEMBERS ABSENT

Senator Lyda Green, Vice Chair

COMMITTEE CALENDAR

SENATE BILL NO. 385

"An Act relating to homeland security, to civil defense, to emergencies and to disasters, including disasters in the event of attacks, outbreaks of disease, or threats of attack or outbreak of disease; establishing the Alaska division of homeland security and emergency management in the Department of Military and Veterans' Affairs and relating to the functions of that division and that department; and providing for an effective date."

MOVED CSSB 385(HES) OUT OF COMMITTEE

CS FOR HOUSE CONCURRENT RESOLUTION NO. 31(HES)

Proclaiming April 2004 as Traumatic Brain Injury Awareness Month.

MOVED SCS CSHCR 31(HES) OUT OF COMMITTEE

CS FOR HOUSE BILL NO. 25(JUD)

"An Act relating to health care decisions, including do not resuscitate orders, anatomical gifts, and mental health treatment decisions, and to powers of attorney relating to health care, including anatomical gifts and mental health treatment decisions; and providing for an effective date."

HEARD AND HELD

PREVIOUS COMMITTEE ACTION

BILL: SB 385

SHORT TITLE: SECURITY;DIV. HOMELAND SECURITY/EMER. MGT

SPONSOR(s): HEALTH, EDUCATION & SOCIAL SERVICES

04/05/04 (S) READ THE FIRST TIME - REFERRALS
04/05/04 (S) HES, FIN
04/05/04 (S) HES AT 1:30 PM BUTROVICH 205
04/05/04 (S) Heard & Held
04/05/04 (S) MINUTE(HES)
04/07/04 (S) -- Rescheduled to 5:30 pm 4/7/04 --
04/07/04 (S) HES AT 5:30 PM BUTROVICH 205

BILL: HCR 31

SHORT TITLE: TRAUMATIC BRAIN INJURY AWARENESS MONTH

SPONSOR(s): REPRESENTATIVE(s) MCGUIRE

02/16/04 (H) READ THE FIRST TIME - REFERRALS
02/16/04 (H) HES
02/26/04 (H) HES AT 3:00 PM CAPITOL 106
02/26/04 (H) Moved CSHCR 31(HES) Out of Committee
02/26/04 (H) MINUTE(HES)
03/01/04 (H) HES RPT CS(HES) NT 6DP
03/01/04 (H) DP: GATTO, WOLF, COGHILL, SEATON,
03/01/04 (H) CISSNA, WILSON
03/24/04 (H) TRANSMITTED TO (S)
03/24/04 (H) VERSION: CSHCR 31(HES)
03/26/04 (S) READ THE FIRST TIME - REFERRALS
03/26/04 (S) HES
04/07/04 (S) -- Rescheduled to 5:30 pm 4/7/04 --
04/07/04 (S) HES AT 5:30 PM BUTROVICH 205

BILL: HB 25

SHORT TITLE: HEALTHCARE SERVICES DIRECTIVES

SPONSOR(s): REPRESENTATIVE(s) WEYHRAUCH

01/21/03 (H) PREFILE RELEASED (1/10/03)
01/21/03 (H) READ THE FIRST TIME - REFERRALS
01/21/03 (H) HES, JUD, FIN
02/13/03 (H) HES AT 3:00 PM CAPITOL 106
02/13/03 (H) Heard & Held
02/13/03 (H) MINUTE(HES)
02/27/03 (H) HES AT 3:00 PM CAPITOL 106
02/27/03 (H) Heard & Held
02/27/03 (H) MINUTE(HES)
03/06/03 (H) HES AT 3:00 PM CAPITOL 106

03/06/03 (H) Moved CSHB 25(HES) Out of Committee
 03/06/03 (H) MINUTE(HES)
 03/10/03 (H) HES RPT CS(HES) NT 7DP
 03/10/03 (H) DP: GATTO, WOLF, HEINZE, SEATON,
 03/10/03 (H) CISSNA, KAPSNER, WILSON
 03/26/03 (H) JUD AT 1:00 PM CAPITOL 120
 03/26/03 (H) -- Meeting Canceled --
 03/28/03 (H) JUD AT 1:00 PM CAPITOL 120
 03/28/03 (H) Heard & Held
 03/28/03 (H) MINUTE(JUD)
 03/31/03 (H) JUD AT 1:00 PM CAPITOL 120
 03/31/03 (H) Moved CSHB 25(JUD) Out of Committee
 03/31/03 (H) MINUTE(JUD)
 04/07/03 (H) JUD RPT CS(JUD) NT 5DP
 04/07/03 (H) DP: SAMUELS, HOLM, GARA, OGG, MCGUIRE
 04/07/03 (H) FIN REFERRAL WAIVED
 05/06/03 (H) TRANSMITTED TO (S)
 05/06/03 (H) VERSION: CSHB 25(JUD)
 05/07/03 (S) READ THE FIRST TIME - REFERRALS
 05/07/03 (S) HES, JUD
 05/16/03 (S) HES AT 1:30 PM BUTROVICH 205
 05/16/03 (S) Heard & Held
 05/16/03 (S) MINUTE(HES)
 03/08/04 (S) HES AT 1:30 PM BUTROVICH 205
 03/08/04 (S) Heard & Held
 03/08/04 (S) MINUTE(HES)
 03/24/04 (S) HES AT 1:30 PM BUTROVICH 205
 03/24/04 (S) Heard & Held
 03/24/04 (S) MINUTE(HES)
 04/02/04 (S) HES AT 1:30 PM BUTROVICH 205
 04/02/04 (S) Bill Postponed to 04/07/04
 04/07/04 (S) -- Rescheduled to 5:30 pm 4/7/04 --
 04/07/04 (S) HES AT 5:30 PM BUTROVICH 205

WITNESS REGISTER

BRIG. GEN. CRAIG CAMPBELL
 Adjutant General for National Guard of Alaska
 Commissioner, Department of Military & Veterans Affairs
 PO Box 5800
 Ft. Richardson, AK 99505-0800

POSITION STATEMENT: Presented SB 385.

MR. DAVE LIEBERSBACH
 Acting Assistant Commissioner
 Office of Homeland Security & Emergency Services

POSITION STATEMENT: Presented Amendment 1 to SB 385.

MR. RYAN MAKINSTER
Staff to Representative Lesil McGuire
Alaska State Capitol
Juneau, AK 99801-1182

POSITION STATEMENT: Presented HCR 31 on behalf of the bill's sponsor.

DR. MARIA WALLINGTON
Medical Ethicist
Providence Alaska Medical Center
Anchorage, Alaska

POSITION STATEMENT: Answered questions pertaining to HB 25.

MS. LINDA SYLVESTER
Staff to Representative Weyhrauch
Alaska State Capitol
Juneau, AK 99801-1182

POSITION STATEMENT: Explained changes to HB 25.

MR. JASON HOOLEY
Staff to Chair Dyson
Alaska State Capitol
Juneau, AK 99801-1182

POSITION STATEMENT: Regarding HB 25, confirmed that version V was previously adopted.

MS. CAROLE EDWARDS
Alaska Nurses Association (ANA)
Juneau, Alaska

POSITION STATEMENT: Provided further input to the current version of HB 25.

MS. LOIS HILDENBRAND
American Cancer Society (ACS)
Fairbanks, Alaska

POSITION STATEMENT: Supports HB 25.

MS. CONNIE JONES
Anchorage, Alaska

POSITION STATEMENT: Suggested that the section on pregnancy be removed from HB 25.

MR. BRUCE ZALNERAITIS
Life Alaska Donor Services
Anchorage, Alaska

POSITION STATEMENT: Answered questions on HB 25 relating to anatomical gifts and consent.

MR. CHIP WAGONER
Alaska Catholic Conference (ACC)
Juneau, Alaska

POSITION STATEMENT: Provided recommendations to the current version of HB 25.

MS. MARIE HELM
Christian Sciences Churches of Alaska
Juneau, Alaska

POSITION STATEMENT: Testified on HB 25, suggesting the inclusion of a patient's right to be transferred home.

ACTION NARRATIVE

TAPE 04-20, SIDE A

CHAIR FRED DYSON called the Senate Health, Education and Social Services Standing Committee meeting to order at 5:45 p.m. Present at the call to order were Senators Wilken, Davis, Guess, and Chair Dyson.

SB 385-SECURITY;DIV. HOMELAND SECURITY/EMER. MGT

The committee took up SB 385.

CHAIR DYSON said his understanding from the commissioners of DPS, DOT and DEC is there are no problems with this, and he hopes to pass the bill out of committee.

BRIG. GEN. CRAIG CAMPBELL, Adjutant General for National Guard of Alaska, and Commissioner for Department of Military & Veterans Affairs, began his testimony by apologizing for not being at Monday's meeting [4/5/04] due to scheduling conflicts. SB 385 refers to the emergency services and civil defense code in statute and makes the necessary adjustments to actively and correctly handle the homeland security mandate that's upon Alaska and every other state. He clarified that the old law refers to districts, and "we're taking all that out." In 1951, when the original code was passed, it was under the civil defense authority that the Senate and the House allowed for establishing districts for civil defense; Alaska never opted to do that, so the decision was made to eliminate that unnecessary reference. Another issue from Monday's meeting was property. It is referenced to be able to confiscate and use property, and

the question was, "Is it real or personal property or both?" That has been reviewed with the attorney, and the way it's written is passive, so it can be either personal or real property. Not just land or structures, but it could include other things necessary to conduct business in Homeland Security.

CHAIR DYSON asked if this included airplanes or boats.

COMMISSIONER CAMPBELL confirmed this was part of the real property and would be covered.

CHAIR DYSON asked, "But only when the governor declares an impending or actual emergency?"

COMMISSIONER CAMPBELL said, "That's the big issue of this whole statute, and that's the important part, is setting up the authority to do this." He said it wouldn't be given to his department or DPS unless the governor declares a higher state of threat and publicly declares it in the state. A disaster policy cabinet then meets and recommends actions that need to be taken to the governor, who in turn has to make the declaration to do that. There's a multi-step process whereby the governor declares the authority to implement that, which would not be allowed in a day-to-day routine operation.

CHAIR DYSON said that under the governor's emergency powers, he "has much of that already" and what's being done here is integrating existing concepts into the new organization and the re-distribution of these responsibilities.

COMMISSIONER CAMPBELL confirmed that was correct. He outlined emergency management today as meeting to declare an emergency, and taking it to the governor who would review and approve it as appropriate. He pointed out the questions for Homeland Security as, "When do you go to a level orange? When do you go to a level red? What do you do at level orange? What do you do at level red?" This establishes a statute allowing for replication of the emergency services process in Homeland Security; that is the intention.

COMMISSIONER CAMPBELL addressed the question, "Do we have any ability to have agreements with Canada, with Canadians?" In this statute, there are several references to having agreements with other jurisdictions, and it specifically mentions "provinces" in two separate places. That was deliberately done to recognize an agreement with Canada and to establish those types of relationships.

CHAIR DYSON said he saw this reference but "provinces" or "other countries" wasn't included in all the sections that refer to coordination. He asked if the inclusion was a logical and legal inference, if it carries through.

COMMISSIONER CAMPBELL said yes, and explained that page 8, lines 14-16 establishes the right for reciprocal aid agreements with other governments, but it doesn't go into details on what those are. This grants the ability to negotiate those agreements with other jurisdictions, including provinces of Canada, to established needs. He referred to the issue of authority, noting that Chair Dyson had not received objection from DPS or DOT on the issue of authority. He explained that currently, when it comes to setting up a checkpoint or a roadblock on a roadway, it's designed to be done - as state troopers and police will do - in response to criminal activity. "We're in a different world in Homeland Security." Establishing a checkpoint on a road where one can't demonstrate there's already been something criminal that's happened is difficult to do without statutory authority. SB 385 absolutely establishes that right and the ability for DMVA, in coordination with DPS to set up those checkpoints.

COMMISSIONER CAMPBELL referred to the checkpoints established at the Dalton Highway in Valdez over the holidays. State defense forces and the National Guard were manning those checkpoints and worked with the state troopers. Although this was executed correctly, lawyers said, "We can't find the authority to execute it." Today at 11:00 a.m., a cabinet meeting with Commissioner Tandeske, Commissioner Barton, and lawyers from those departments reviewed SB 385 and the proposed amendments, ensuring concurrence that the authority was written properly. He said he was satisfied that, as written, SB 385 allows for manning the checkpoints. Commissioner Tandeske is satisfied that it keeps public safety's control of checkpoints, blockages, and rights-of-way.

MR. DAVE LIEBERSBACH, Acting Assistant Commissioner for the Office of Homeland Security and Emergency Services, and the Director of Division of Emergency Services within DMVA, presented Amendment 1.

SENATOR GRETCHEN GUESS moved Amendment 1.

CHAIR DYSON objected for purposes of discussion.

MR. LIEBERSBACH reviewed the following changes incorporated in Amendment 1 [made available from DMVA]:

Page 3, line 18

Following "coordinate"
Insert "with"

Page 6, lines 6-10:

Delete "(14) when the governor orders state action in response to a high or severe threat of attack, at the direction of the governor and in coordination with the Department of Public Safety, establish and operate checkpoints for the reasonable inspection of persons and vehicles for weapons or explosives, using state roads, state property, or state facilities"

Page 10, line 19:

Following "designee"
Insert "of the adjutant general, in consultation with the commissioner of public safety or a designee of the commissioner of public safety,"

Page 10, following line 19:

Insert a new bill section to read:

*Sec. 9. AS 26.20.100 is amended to read:

Sec. 26.20.100. Traffic control. In coordination with the department of public safety and the department of transportation and public facilities, the [THE] department may

(1) formulate and execute plans and regulations for the control of traffic for the rapid and safe movement of evacuation over public highways and streets of people, troops, or vehicles and materials for homeland security and civil defense [NATIONAL DEFENSE OR FOR USE IN A DEFENSE INDUSTRY, AND MAY COORDINATE THE ACTIVITIES OR AGENCIES OF THE STATE AND OF THE DISTRICTS CONCERNED WITH PUBLIC HIGHWAYS AND STREETS, IN A MANNER THAT WILL BEST CARRY OUT THOSE PLANS]; and

(2) establish and operate checkpoints along private or public roadways serving critical property or facilities in the state, at the direction of the governor when the governor determines that a sufficiently high threat of attack exists to warrant such action. The checkpoints established under this subsection may be in conjunction with closure of the roadway under AS 19.10.100. Operation of a checkpoint shall be limited to enforcement of the roadway closure or reasonable inspection of persons and

vehicles for weapons, explosives, chemicals, biological or biochemical agents, or other instruments capable of causing widespread of severe injury to persons or property.

Renumber the following bill sections accordingly.

Page 14, line 5:

Delete "firearms,"

Insert "[FIREARMS,]

Page 15, line 26

Delete "26.20.100,"

MR. LIEBERSBACH explained that "firearms" was deleted because it might raise concerns related to the 2nd Amendment of the U.S. Constitution, the right to bear arms. The limit of sale and dispensing was as much a concern as was limiting the transportation of firearms, i.e. not being able to carry hunting rifles in vehicles.

CHAIR DYSON asked if this change would reduce the department's authority to take away an illegal firearm if, for example a felon had a firearm.

MR. LIEBERSBACH said it does not reduce that capacity, and the authority lies with the troopers; they still have all of their authority.

CHAIR DYSON asked if National Guard forces, under a declaration of emergency, have similar police powers to troopers, even though this is structured so that they will be working under the supervision of a trooper.

MR. LIEBERSBACH stated that the last change should not read as the deletion of "26.26.100" but rather, as follows:

Page 15, line 26

Delete "26.20.100"

This would not repeal "26.20.100."

CHAIR DYSON moved to amend Amendment 1 to make the above noted change. He asked if there was any objection. There being none, Amendment 1 was amended.

CHAIR DYSON removed his prior objection to Amendment 1 and asked if there were further objections. Seeing none, Amendment 1 was adopted.

CHAIR DYSON told Senators Davis and Guess that if they came up with anything bothersome regarding the bill, he would make sure there would be an opportunity to address those concerns in the Finance Committee. He confirmed, with Senator Wilken, the co-chair of Finance, that this would be acceptable.

CHAIR DYSON asked for the wish of the committee.

SENATOR WILKEN moved to report SB 385 as amended [CSSB 385(HES)] from committee with individual recommendations and accompanying fiscal note.

CHAIR DYSON asked if there were any objections. Seeing and hearing none, it was so ordered.

6:05 p.m.

HCR 31-TRAUMATIC BRAIN INJURY AWARENESS MONTH

MR. RYAN MAKINSTER, staff to Representative Lesil McGuire, presented CSHCR 31(HES) on behalf of the sponsor. He began by telling members that there was a request for an amendment that would proclaim May rather than April as Traumatic Brain Injury Awareness Month. He explained that every 21 seconds someone in the U.S. sustains a traumatic brain injury (TBI), which equals more than 4,000 people daily. Of the approximately 1,500,000 people who suffer these injuries annually, 50,000 die while another 80,000 sustain life-changing injuries. In Alaska alone at least 600 people receive acute care for brain injuries, 150 Alaskans die, and another 190 experience the onset of lifelong disabilities because of traumatic brain injuries. TBI is not something that one can find a cure for and it is not a disease. They are the result of accidents. The only way to lower these numbers is to increase awareness. Males below the age of 30 have a higher risk of TBIs. A lot of professional skaters, skiers, and snowboarders wear helmets now; people should wear helmets and seatbelts to lower the incidence of injury.

MR. MAKINSTER offered the background information that Representative McGuire's younger brother - who is his same age - experienced a head-on collision during his senior year and was in a coma for three months. He came out of the coma, graduated from high school, went to college and is a productive citizen in

society but, he has lifelong disabilities including a speech impediment. The jobs that were available to him are no longer available. Mr. Makinster told members that one of his close friends was involved in a jet-ski accident in Idaho and was in a coma for six months. He had been a straight-A student, all-star athlete, had a full scholarship to Washington State University to play football. Subsequently he had to drop out of school for two years for rehabilitation. He did eventually graduate from college with a 4.0; however, he has to take expensive medication for the rest of his life.

MR. MAKINSTER respectfully requested that three changes be made to HCR 31. The first change would be on page 1, line 1, changing "April" to "May" of 2004. Also, an associated change would be to change the language to "May" on page 2, line 6. The reason for this change is because today's date is already partially through April, 2004. Also this would then be in concert with the Kenai Peninsula's TBI Awareness Week. The third change would be to insert "Alaska Traumatic Brain Injury Advisory Board" after the word "the" on page 1, line 14.

CHAIR DYSON moved to amend CSHCR 31(HES) to change the date to reflect May instead of April of 2004, and to include the "Alaska Traumatic Brain Advisory Board" and asked if there was any objection. Seeing and hearing none, those amendments were adopted.

CHAIR DYSON thanked Mr. Makinster, noting that perhaps someone would be saved or would receive support as a result of increased awareness.

SENATOR GRETCHEN GUESS moved to report CSHCR 31 as amended [SCS CSHCR 31(HES)] out of committee with individual recommendations and the accompanying zero fiscal note.

CHAIR DYSON asked if there was any objection. There being none, it was so ordered.

6:10 p.m.

The committee took an at-ease from 6:10 - 6:15 p.m.

HB 25-HEALTHCARE SERVICES DIRECTIVES

The committee took up CSHB 25(JUD).

DR. MARIA WALLINGTON, medical ethicist at Providence Alaska Medical Center in Anchorage, acknowledged that a great deal of work has been done on the bill since it passed the House, and that she was looking forward to enactment of the bill. She indicated that she needed to catch a plane, but could answer questions for several minutes.

CHAIR DYSON said HB 25 would be heard on Wednesday [April 14] and confirmed that she would be available by telephone. He then asked Dr. Wallington if a person has an advance directive and an agent, if that agent can make the health care decisions.

DR. WALLINGTON said that is correct.

CHAIR DYSON asked if the agent could over-ride what the person included in the advance care directive.

DR. WALLINGTON responded, "No, they can't. They are instructed to make decisions that support and work for the health care directives that the patient has given in their directive." If the particular issue is not addressed in the directive then it would follow what the agent knows of the person's wishes or values. If those are not pertinent or unknown, the agent is instructed to work according to the best interest of the principal.

CHAIR DYSON asked if the agent was the only one to define those best interests or if there was a medical team involved in that decision.

DR. WALLINGTON said the decisions were generally shared. The medical personnel have a great deal of input because of knowing the medical issues and the benefits/risks of treatment.

CHAIR DYSON asked about the meaning of the phrase "inhumane burden."

DR. WALLINGTON said to her it means that what this person is going through seems pretty awful.

CHAIR DYSON asked if this were something other than pain and suffering.

DR. WALLINGTON answered it seems an inhumane burden would lead to suffering. She noted that she didn't pick that terminology and had a similar question about the meaning. She explained that people can experience physical pain and suffering; there

can be emotional suffering from not being able to speak and knowing it; there can be spiritual suffering also. She said she wasn't sure what amounts to an inhumane burden, but that she hopes the medical people and the agent would recognize a situation as being too much.

CHAIR DYSON asked about someone other than the patient making that decision when the patient is incompetent or unconscious.

DR. WALLINGTON interjected, a person not capable of expressing his/her opinion.

CHAIR DYSON continued that a conscious and competent patient makes his/her own decisions, no matter what the agent or the directive says. However, if a non-terminal patient (someone who is not going to die really soon) is unconscious, and is experiencing pain and suffering, then the directive, the agent, and the best interest would indicate the use of pain medications to deal with the suffering.

DR. WALLINGTON confirmed, "If the suffering is from the pain."

CHAIR DYSON asked at what point - under what circumstances - regarding an incompetent or unconscious person who is not terminal, ought the decision be made to withdraw hydration and food to let the person die.

DR. WALLINGTON said one has to go back to the word "terminal" and ask if the only reason a person is still living is because of being provided with some kind of medical care, is that person terminal if you can force him/her to keep on living? That is, if someone would die without medical care, is that person terminal? Or, if you can keep them alive with medical care, are they not terminal? It's a grey area because obviously, a diabetic without insulin will die, but that person wouldn't be referred to as terminal. She said that for her personally, it hinges on whether what is needed to keep the person alive actually allows him/her to go on with life, or if there is hope for that person to become healthy again and not depend on that medical care. She said so much depends on the particular situation, giving absolute criteria is very difficult.

CHAIR DYSON said he doesn't think of someone on a ventilator or an oxygen bottle as being terminal. If a person has a degenerative condition that's going to terminate his/her life, and medical attention is supporting them, but can't reverse them...

Dr. WALLINGTON interjected, "It's irreversible and progressive."

CHAIR DYSON continued by asking, "If the best knowledge is that the person is not going to return to consciousness, what criteria should be used to decide whether that person - who is heading downhill in a reasonable period of time, with no good chance of returning to consciousness - decide whether or not to stop the support that's keeping that person alive?"

DR. WALLINGTON asked, "Thinking of yourself as the deciding agent, and the physician?"

CHAIR DYSON replied, "No, you as the ethical guru on this who helped to guide us all with your training and experience."

DR. WALLINGTON recalled that previous discussion regarding best interest was "how we're trying to capture this decision-making process, is [through] the patient's values." As an example she mentioned that in Orthodox Judaism there is a belief that the life of the body is an absolute good and therefore what is required to keep the body functioning would be aligned with that value. She said her personal value system is that if she wasn't conscious of her interactions with others and God, then she wouldn't want her body kept alive. She emphasized that personal values should be weighed in the balance and need to be a part of the decision. The value of having a surrogate who knows you is that he/she can express what you have expressed to him/her. Dr. Wallington informed members she had to leave the meeting to catch a plane.

SENATOR GUESS stated that she was working from version B and she wondered whether the rest of the committee was also working from version B.

CHAIR DYSON said no, "We're still working off of the last version that we had."

MS. LINDA SYLVESTER, staff to Representative Weyhrauch, clarified that version B was from "Legislative Legal" and it contained a correction that was mission from version V. She said, "'V' is the operative, 'W'; and 'B' has ... two changes." A definition of "enucleator" was taken out, as it doesn't exist in the state and is pretty irrelevant to the discussion. The only substantive change is the first statement in the form, a caution or a warning about Alaska, it does not honor suicide - assisted suicide, euthanasia - and since it is repeated in the

form, it was taken out of the introduction to the Optional form. That is the difference between versions B and W. There are substantial changes from versions V to W, but version B is essentially the same as 'V.'

CHAIR DYSON asked if the last committee action taken was to adopt version V.

MR. JASON HOOLEY, staff to Chair Dyson, confirmed that was correct, version V was adopted during the 3/24/04 meeting.

MS. SYLVESTER continued that at the last hearing, her instructions were to accumulate comments and amendments, and the results of that are dramatic improvements to 'V'....

CHAIR DYSON clarified that version V was before the committee.

MS. CAROLE EDWARDS, a board member of the Alaska Nurses Association (ANA), and an oncology nurse for over 20 years, testified that she has given direct care to many patients at the end of life. She referred to a phrase, "even if it should hasten my death" from one of the versions pertaining to pain medication. She asked Ms. Sylvester for the page number of this reference.

MS. SYLVESTER said in the form there is an option for an individual filling out the advance health care directive to choose "Relief from Pain." The preferred language is, "I direct that treatment for the alleviation of pain or discomfort be provided at all times." It has been proposed to continue that statement by stating, "even if it kills me, even if it hastens my death, even if it causes my death." She said "the sponsor resists that and our position is encouraged by the medical field." Ms. Sylvester said this was what Ms. Edwards was referring to.

CHAIR DYSON questioned whether she said the sponsor resists this.

MS. SYLVESTER confirmed this was so. She said it was preferable that "it should be neutral" about causing or hastening death.

MS. EDWARDS said ANA would like the language in version Q, pages 21-22, under "(8) Relief from Pain: If I mark this box, I direct that treatment to alleviate pain or discomfort should be provided" to be included, but to eliminate "even if it hastens my death." She explained that ANA's view is that most

individuals don't have significant background regarding pain medication at the end of life. People reading this phrase might not understand the need for large doses of pain medication and might be tempted to not check this box for fear that someone might intentionally kill them or hasten their death. These same people might find that in facing a very painful death, the wish is to reverse this decision, but they are unable to do so, not being competent or conscious at that time. Family members not wanting to lose their loved one or not wanting to change the written wishes, might hesitate to allow adequate amounts of pain medication to be given at that point. If this phrase were eliminated it would cause less confusion.

MS. EDWARDS continued that health care providers don't give pain medication to hasten death; it is given to relieve pain. That is the goal. The bottom line for a lot of health care providers is that they don't want to lose their licenses. She said that regarding the entire bill, no matter what one's beliefs are, everyone has the right to make these important decisions for his/her end of life, with the surrogate being aware of those wishes. She said she wants her wishes honored at the end of her life. She wants her parents' wishes honored, and as an only child, she knows exactly what they want and she plans to follow their wishes. She hopes that they're in New Jersey, because that state will allow her to follow their wishes. She hopes that Alaska will allow for her wishes and her patients' wishes to be followed, and for people to make their own decisions.

CHAIR DYSON asked what New Jersey does that other states don't do.

MS. EDWARDS said that her parents' advance directives are filled out, indicating "nothing at the end of life." They don't want CPR, artificial fluid and nutrition, or life support. They want I-V fluids only if it's to deliver pain medication so they are comfortable at the end of life.

CHAIR DYSON asked if New Jersey allows a person to make the choice for virtually no life support at the end of life.

MS. EDWARDS said yes. She added that she has the durable power of attorney for health care to make those decisions for her parents.

Tape 04-20, SIDE B

MS. LOIS HILDENBRAND, a volunteer with the American Cancer Society (ACS), testified from Fairbanks that ACS supports provisions of the current version of the bill. The society supports the rights of patients and their loved ones to make informed decisions about their health care, and it should be clear and uniform so patients' wishes may be respected and suffering may be diminished. She then told members that she practiced as a nurse in Alaska from 1982 until 1998 and is currently a pastor at the University Community Presbyterian Church. She offered an anecdote about her uncle who was in nursing care after a life-threatening event. She was a witness to his "do not resuscitate (DNR)" order in Anchorage. He was then transferred to Fairbanks where his family is located. A year after he was transferred he noticed a little blue dot on the plate card in the dining room at the Denali Center. When he found out that this blue dot was for people who had DNR orders he said that he had such an order, but the nurse taking care of him said that he didn't. The one he had signed in Anchorage did not transfer to Fairbanks. Fortunately this wasn't an issue; however, had an event occurred, he would have been resuscitated which would have been against his will. She commended this attempt to make things uniform throughout the state so that situations like this would not be faced in the future.

6:40 p.m.

MS. CONNIE JONES, a reverend and associate rector at St. Mary's Episcopal Church, said she wasn't speaking on behalf of the church, but was speaking for herself. She said she is very supportive of the bill, and expressed her strong concern that on page 8, regarding a section on pregnancy, there is language that takes away some freedom from the physician, patient, and surrogate. It says that certain health care decisions may not be given effect under certain circumstances dealing with pregnancy. She suggested this subject was for some other bill rather than for this one, and that there would be more widespread support of the bill if that section were removed.

CHAIR DYSON said he thought that he and the sponsor were in agreement, but it was his assumption that a woman who is comatose and unable to make decisions - the fact that she is carrying an unborn child - is evidence that she wants that child to survive unless there is information to the contrary. He said he believed the sponsor was interested in the implied, if not expressed, wish for this to be carried forward and asked Ms. Jones what the problem was with that.

SENATOR GUESS asked for clarification of the version being addressed.

CHAIR DYSON responded this was on page 8 in version V.

MS. JONES wondered if she had the correct version, as she had version V. [It was clarified that this also referred to page 8, line 16, version B.] Ms. Jones continued that she didn't see any definition relating to this section, in the back. She was looking, in particular for a definition of "fetus" as she didn't know what stage was being referred to.

CHAIR DYSON said he thought he was speaking for the sponsor, but the assumption was that if a woman was pregnant and hadn't already made the choice to, or wasn't already in the process of getting an abortion, then this was a wanted child, so the default choice would be to preserve that woman's life as long as possible to enhance the child's chances of surviving her.

MS. JONES suggested that this kind of detail does not belong in the bill and her hope was that the physicians dealing with this person and the surrogate, if the woman was comatose, would use judgment and not have to be given an instruction indicating that these health care decisions "may not be given effect." She reiterated that the bill doesn't suffer by having this language removed, and said it sounds a little dictatorial. Ms. Jones asked about obtaining updated versions of the bill.

CHAIR DYSON pointed out that the language she had referred to had not changed [between versions] and said she could contact either his office or Senator Guess's for updated versions.

MR. BRUCE ZALNERAITIS, with Life Alaska Donor Services in Anchorage, the state's organ and tissue donor program, testified that he was available to answer questions relating to anatomical gifts and consent, particularly to what is called "first person consent or donor designation."

CHAIR DYSON asked if Life Alaska Donor Services is a program or a commercial enterprise.

MR. ZALNERAITIS replied this is a non-profit organization responsible for organ and tissue donations in the state. He mentioned that he has made recommendations to the bill.

CHAIR DYSON asked if he was uncomfortable about the direction the sponsor was going with the bill.

MR. ZALNERAITIS said no. He referred to the question of opting out as opposed to opting in. Life Alaska supports the system now in place in which a person chooses to be a donor, and until he/she does so, is not a donor. That could be described as an opt-in system. A person needs to indicate, through a donor registry or the completion of a donor card, that he/she wishes to be a donor. In the absence of that, he/she is not a donor unless upon his/her death, the family chooses to grant permission for him/her to be a donor.

CHAIR DYSON asked if the current donor law is opt-in.

MR. ZALNERAITIS said yes, and that means that based on the Uniform Anatomical Gifts Act that Alaska has adopted, Life Alaska is not able to proceed with a donation unless either the person has granted permission in advance, or his/her relatives - upon that person's death, in the order described - granted permission for donation. It does not take place without such permission.

CHAIR DYSON asked if it is correct that the agent, surrogate, or guardian could not overrule a person who gave an advance directive indicating they did not want to be a donor.

MR. ZALNERAITIS said correct. In accordance with the Uniform Anatomical Gifts Act, if a "known prior objection" exists from the person, or in the case of after death, the deceased, donations shall not take place.

CHAIR DYSON questioned whether the family could make those decisions after death if the person didn't write it down.

MR. ZALNERAITIS said correct. This would be considered as "no known objection."

CHAIR DYSON asked for clarification about a situation in which a person has flat-line brainwaves, and the current practice to keep the heart and lungs going, while the team gets ready and/or prepares the recipients and whether it is within the realm of commonly defined ethics.

MR. ZALNERAITIS said the first step is to consult with the next-of-kin to determine whether, in the absence of advance notation to be a donor, the family would grant permission to consider their loved one as being a donor. Only then would organ function get assessed and teams be brought in to do the transplants.

CHAIR DYSON asked if there were any states that had opted-out.

MR. ZALNERAITIS said there are no opt-out systems in the United States that he knows of.

MR. CHIP WAGONER, representing the Alaska Catholic Conference (ACC), testified that ACC is the official voice of the church in Alaska regarding public policy matters. He emphasized the significance of the bill, with its goal to enable individuals to have their wishes implemented. He stated that ACC has the goal of wanting to prohibit and prevent euthanasia; euthanasia is defined as "an action or an admission which of itself or by intention causes death in order that all suffering may in this way be eliminated." He said this was a balance of two very important public policies, and Chair Dyson's version X comes closest to meeting that balance. He referred to version X, saying that of the 14 amendments ACC submitted, 3 were accepted, 4 were compromised, and 7 were rejected. Regarding version B, 12 were rejected, 1 was compromised, and 1 was accepted. He mentioned a change in ACC's recommendation regarding two situations in which life-sustaining procedures could be withheld or withdrawn from a patient, when it was determined by the surrogate, agent, or guardian. One situation was when the person was terminally ill, and the other was when a person was permanently unconscious. Since those amendments were submitted, there was a conference held in Europe sponsored by the Pontifical Academy for Life and the International Federation of Catholic Medical Associations, the International Congress of Life Sustaining Treatments and Vegetative State Scientific Advances and Ethical Dilemmas. Pope John Paul II issued a statement at that conference relating to the issue of when artificial nutrition and hydration could be withheld or withdrawn, and ACC is backing off from that amendment somewhat, although it may not change ACC's support for the bill.

CHAIR DYSON asked what position the group came to that was authenticated by The Pope.

MR. WAGONER read the following: "I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. It's use, furthermore, should be considered in principle ordinary and proportionate and as such, morally obligatory insofar as and until it is seen to have attained its proper finality, which in the present case, consists in providing nourishment to the patient and alleviation

of his suffering." Mr. Wagoner stated that this was a stronger position and that regarding version X ...

CHAIR DYSON interrupted, saying that this was a bit of a problem because [version X] had not been distributed yet, and he hadn't had a chance to look at it; it was not yet a part of the active discussion.

SENATOR GUESS reiterated that it was disturbing that she had received version B from the sponsor, "which is after X, and a W, and that there's an X floating around" and that she wasn't being provided with the version Mr. Wagoner was speaking to.

MR. WAGONER apologized and said, "I think we're very, very close, Mr. Chairman."

CHAIR DYSON agreed, stating that the sponsor and his staff have done immense and valuable work.

MR. WAGONER confirmed, "Without a doubt, I think you've brought two of the ends kind of in the middle, and if the middle survives that would be great."

CHAIR DYSON encouraged members to bring any specifics on the bill to his staff in order to achieve the very best product because "this is such a laborious effort that I doubt if we'll be back visiting it for a long time, and we're setting a course here that makes a huge difference for a small but significantly impacted group of people."

SENATOR GUESS said it was difficult to provide comments when the version being worked from is unspecified and there are two different versions being drafted by Legislative Legal. She said she provided comments to the sponsor and his staff, and she spent time with Dr. Wallington as well.

CHAIR DYSON responded that there would only be three, four, or five places with changes. He added, "We'll try to highlight those for you."

MR. WAGONER asked to speak to the pain management issue. He said there are two reasons why ACC advocated for having something that the patient could put on his/her form regarding pain management to alleviate discomfort and pain. ACC wants something included to the effect that "it's not being done with the intention of causing their death." The language may need to be re-worded, but it's included to alleviate the fear that

doctors may have of prescribing pain medication, and secondly to clarify that euthanasia or assisted suicide is not being authorized.

CHAIR DYSON asked if there was any further testimony.

7:03 p.m.

MS. MARIE HELM, representative of the committee on publication for the Christian Sciences Churches of Alaska, expressed support for HB 25 and commended Representative Weyhrauch, his staff and the HES committee for their work. She referred to language in version V on page 10 that talks about allowing a patient to transfer from a facility. She stated that she hopes that it could be spelled out that a patient could choose to go home where there might be hospice care or other alternative treatments because there might be times that this would be the right choice for an individual.

CHAIR DYSON asked where that was on page 10.

MS. HELM replied that the language was on line 12, page 10 of version B. She suggested adding language such as, "a location of the patient's choice or the patient's home" saying it would be nice to include that so it would be understood that it's the patient's right to choose to go home.

CHAIR DYSON said that is a good point and thanked her for her contribution.

CHAIR DYSON held CSHB 25(JUD) in committee.

There being no further business before the Senate Health, Education and Social Services Standing Committee, CHAIR DYSON adjourned the meeting at 7:05 p.m.