ALASKA STATE LEGISLATURE
SENATE HEALTH, EDUCATION AND SOCIAL SERVICES STANDING COMMITTEE
March 8, 2004
1:33 p.m.

TAPE(S) 04-12

MEMBERS PRESENT

Senator Fred Dyson, Chair
Senator Lyda Green, Vice Chair
Senator Gary Wilken
Senator Bettye Davis

MEMBERS ABSENT

Senator Gretchen Guess

COMMITTEE CALENDAR

HOUSE BILL NO. 282
"An Act relating to contracts between the University of Alaska and its employees involving research or other development of intellectual property and to the authority of the president of the University of Alaska regarding employee contracts for development of intellectual property."

MOVED HB 282 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: HB 282
SHORT TITLE: UNIVERSITY EMPLOYEE RESEARCH CONTRACTS
SPONSOR(s): REPRESENTATIVE(s) FATE

04/23/03	(H)	READ THE FIRST TIME - REFERRALS
04/23/03	(H)	HES, L&C
05/15/03	(H)	HES AT 3:00 PM CAPITOL 106

05/15/03	(H)	Scheduled But Not Heard
01/22/04	(H)	HES AT 3:00 PM CAPITOL 106
01/22/04	(H)	Moved Out of Committee
01/22/04	(H)	MINUTE(HES)
01/23/04	(H)	HES RPT 3DP 1NR
01/23/04	(H)	DP: CISSNA, SEATON, WILSON; NR: GATTO
02/02/04	(H)	L&C AT 3:15 PM CAPITOL 17
02/02/04	(H)	Moved Out of Committee
02/02/04	(H)	MINUTE(L&C)
02/04/04	(H)	L&C RPT 4DP 3NR
02/04/04	(H)	DP: CRAWFORD, ROKEBERG, GUTTENBERG,
02/04/04	(H)	ANDERSON; NR: LYNN, GATTO, DAHLSTROM
02/19/04	(H)	TRANSMITTED TO (S)
02/19/04	(H)	VERSION: HB 282
02/20/04	(S)	READ THE FIRST TIME - REFERRALS
02/20/04	(S)	HES
03/03/04	(S)	HES AT 1:30 PM BUTROVICH 205
03/03/04	(S)	Heard & Held
03/03/04	(S)	MINUTE(HES)
03/08/04	(S)	HES AT 1:30 PM BUTROVICH 205

BILL: HB 25
SHORT TITLE: HEALTH CARE 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

WITNESS REGISTER

REPRESENTATIVE HUGH FATE
Alaska State Capitol
Juneau, AK 99801-1182
POSITION STATEMENT: Sponsor of HB 282.

MR. JIM POUND
Staff to Representative Fate
Alaska State Capitol
Juneau, AK 99801-1182
POSITION STATEMENT: Answered questions pertaining to HB 282.

REPRESENTATIVE BRUCE WEYHRAUCH
Alaska State Capitol
Juneau, AK 99801-1182
POSITION STATEMENT: Sponsor of HB 25.

DR. MARIA WALLINGTON
Providence Alaska Medical Center
Anchorage, Alaska
POSITION STATEMENT: Supports HB 25.

FRANCIS NOLAN
Anchorage Emergency Medical Services
Anchorage, Alaska
POSITION STATEMENT: Supports HB 25, with expressed concern.

MS. CAROLE EDWARDS
Alaska Nurses Association (ANA)
Juneau, Alaska
POSITION STATEMENT: Supports HB 25.

MS. MARIE DARLIN

AARP Alaska Capital City Task Force
Juneau, Alaska
POSITION STATEMENT: Supports HB 25.

MS. LINDA SYLVESTER
Staff to Representative Weyhrauch
Alaska State Capitol
Juneau, AK 99801-1182
POSITION STATEMENT: Answered questions pertaining to HB 25.

MR. CHIP WAGONER
Alaska Catholic Conference
Juneau, Alaska
POSITION STATEMENT: Supports HB 25, with suggested amendments.

ACTION NARRATIVE

TAPE 04-12, SIDE A

CHAIR FRED DYSON called the Senate Health, Education and Social Services Standing Committee meeting to order at 1:33 p.m. Senators Green, Wilken, Davis, and Chair Dyson were present at the call to order. Also present were Representatives Fate and Weyhrauch. He announced the committee would take up HB 282 and HB 25 and that his intention was to hear public testimony on HB 25 and to hold the bill in committee for resolution of issues.

HB 282-UNIVERSITY EMPLOYEE RESEARCH CONTRACTS

REPRESENTATIVE HUGH FATE, the bill sponsor, testified that HB 282 allows the president of the university to contract with an employee of the university for intellectual property specific to the research done by that employee. This contractual arrangement benefits not only the university, but also the state because of the potential for accrued proceeds from these business relationships through profit and royalties. This takes pressure off of recruitment and helps to retain top professors; it supplements their incomes, but also supplements the income, regard, and prestige of the university for which they work. The bill has been held up before because of regulations concerning ethics, as it's not allowed under current statute and regulation. Many universities have done this. For example, there were over 500 patents from Stanford alone, this past year. This also takes pressure off of the general fund in the event that business enterprises are wildly successful.

SENATOR LYDA GREEN expressed concern. She referred to the third paragraph of President Mark Hamilton's letter of support and read as follows: "Such constraints tend to force researchers to choose between exporting their intellectual property without continuing support, and giving up their university employment. This climate provides little incentive for researchers to focus on technologies that are subject to commercialization." She said it seems simple that during an employee's tenure as a professor or researcher - whether through grant, federal, or state funding – that the information gained would certainly be the university's property as well. She remarked that the issue is that an employee can leave with that intellectual property without the university accruing anything. "I have an idea that problem is bigger than we are, and that's probably a subject of debate all across universities in the world." She pointed out that in the private market this would never be allowed.

REPRESENTATIVE FATE said he couldn't specifically answer that concern, but those items would probably be taken up in the contracts and agreements. "In our particular case because we have not done much of this, it would be uncertain in my mind."

SENATOR GREEN responded that this was a very important issue to be taking up, emphasizing that the protection of that information and the benefit accruing to the university - if it's done in the university lab, on computers, with help, with the whole thing that goes with it – was her main concern.

CHAIR DYSON asked if contrary or negative testimony had been heard on this bill.

MR. JIM POUND, Staff to Representative Fate, responded that negative comments had not been offered in the other body's committee process.

SENATOR GARY WILKEN moved to report HB 282 from committee with individual recommendations [and zero fiscal notes, as mentioned by the Chair].

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

1:50 p.m.

HB 25-HEALTH CARE SERVICES DIRECTIVES

CHAIR DYSON began the hearing on HB 25 [CSHB 24(JUD)] by mentioning that Representative Weyhrauch had made considerable improvements on the bill and that it was [the Chair's] opinion that the "do nothing" option was not a good one. He informed members that after hearing from Representative Weyhrauch, [Chair Dyson] would outline six policy questions for the committee to focus on, followed by public testimony - with the intent to incorporate and accommodate concerns - and to move the bill out of committee in the next 10 days or two weeks.

SENATOR GREEN moved to adopt version U [labeled 23-LS0137\U, Bannister, 2/11/04] as the working document.

CHAIR DYSON asked if there was any objection. There being none, version U was before the committee.

SENATOR WILKEN asked if there was a referral to Senate Finance and received confirmation that there was not.

CHAIR DYSON pointed out that there was a zero fiscal note.

REPRESENTATIVE BRUCE WEYHRAUCH, sponsor of HB 25, told members that if it were not for Chair Dyson's spiritual, emotional, and policy insights, the bill would be "poor for it." As an editorial comment, he said HB 25 was difficult to deal with because it addresses fundamental questions of life and death, and of losing a loved one. He testified that HB 25 was inspired by a concept called the five wishes, and reflects how a person is treated at the end of life according to those wishes in areas such as who will be making those decisions, which decisions to make, the relative comfort during the dying process, and what loved ones should know about end-of-life healthcare decisions. The policy issues are significant and affect decisions such as withholding of food and water, and determining that the environment is – as much as possible – a loving one that is free of judicial intervention. There have been major cases in the U.S. (Florida, Missouri, and elsewhere) dealing with whether treatment should be withheld from someone who is in a vegetative state. He said that at some point policy decisions need to be made and he is glad to have the debate on record. He acknowledged that this bill has been in the Senate before, that he has worked very hard on it, and welcomes dialogue and debate to address concerns.

CHAIR DYSON then outlined six questions as follows:

1. Do we want this legislation to always start with the presumption that when in doubt, we work to preserve life?

2. At what point can an advance directive, an agent, or the surrogate direct that artificial nutrition and hydration - food and water - be withheld?

CHAIR DYSON commented that before looking into this issue, he would have said "of course" [to providing food and water] because to do otherwise would be involved with euthanasia, and he is not personally willing to go there.

3. Reciprocity. How do we handle an end-of-life directive that comes to us from another state that may have different rules, different constraints, and different assumptions?

4. Who is qualified? What is a qualified patient? If you were to push the logic, all of us are in the process of dying, and with the present technology, are terminal. At what point in that process does the definition of 'being qualified' kick-in?

5. Anatomical gifts. That's when parts of the dying or dead person will be transplanted to help someone who is living.

6. Authority of decision-makers. When you have an incompetent patient, no longer capable of making decisions on [his/her] own, and those decisions have been given to a third person. You'll see in the bill a hierarchy of presumption regarding who those 'third persons' are who will make those decisions and how authority or position is gained, and whether there ought to be any appeals to that.

CHAIR DYSON said he probably knows of more reprobates than others do, and cited three instances in Alaska from the last year. He mentioned one example as that of an 87-year old man who had not been out of bed for three years, was marginally conscious, and who all of a sudden fell in love with his 34-year old caretaker and demanded a marriage. The marriage was performed with almost no witnesses present, and the man died five days later. The estate went to the new bride, at the exclusion of the family. "And lo and behold her boyfriend was the doctor prescribing the medicine." He emphasized that care

needs to be taken in situations involving people with vested interests. He referred to two situations in which the will was predicated on death order, meaning who died first determined "where the estate went." Manipulation can occur so that "who becomes an heir depends on who dies first."

DR. MARIA WALLINGTON, a medical ethicist at Providence Alaska Medical Center, testified in support of HB 25, saying that she has been working with Representative Weyhrauch's office and that she was available to answer questions of a medical or ethical nature that might come up.

FRANCIS NOLAN, Anchorage Emergency Medical Services, testified in support of HB 25. He expressed concern about a section of the bill no longer included in the bill's current version U. He also mentioned support for Alaska's Comfort One Program.

MS. CAROLE EDWARDS, an oncology nurse in Juneau for over 20 years and board member of Alaska Nurses Association (ANA), expressed ANA's strong support of HB 25 and testified as follows:

> Death is something that we all must face. The type of death we have can be in a large part within our own control. HB 25 allows us to outline the treatment we do – or don't want – in our last days. Death can be a beautiful and peaceful experience for the patient as well as the family and friends. Or it can be extremely traumatic, painful and stressful for all involved. I have been with many patients at the time of death and have seen both.
>
> I would like to tell you two stories about a good death and a bad death. The first occurred several years ago for a gentleman who was dying from cancer. He had made his wishes known. He was in the hospital. As death was imminent, family and friends gathered at his bedside. I entered the room to feel a sense of peace wash over me. Friends and family were in a circle, holding hands with each other and with the patient, and one member was strumming a guitar gently as the group softly sang, "May the Circle Not be Broken." The patient died in this beautiful setting. This death made a huge impact on me, as I know that this is how it should be. No fear, no writhing in pain, and no dissention among the family members. I

think of this experience often and I would wish it for everyone.

The other death was far different. The patient had terminal cancer. Treatment was extremely difficult, uncomfortable, and the patient was clearly not responding. This was a woman with several adult children. The patient wanted to stop her treatment. One child supported this; the two others did not. Major arguments, even screaming matches broke out in the hospital halls and in the patient's room, among the siblings and with the patient. If this woman had filled out advance directives and a durable power of attorney, we as health care providers could have more easily stepped in. This woman died a very stressful death. The children were not even speaking to each other as they left the hospital. I don't even know if they ever reconciled. Nobody deserves this.

2:10 p.m.

I have also been asked to speak today about fluid and nutrition and pain control for terminally ill patients. First I will address fluid and nutrition. Nutrition in this instance refers to a feeding tube being placed; IV, fluids. If a person, at the end of life, in terminal care, desires something to eat or drink, this does not mean that we would not allow them to have it. They would certainly be allowed to have whatever they want.

Withholding fluid and nutrition allows a patient to die naturally. Before we had the technology to provide IVs and feeding tubes, patients in the dying process naturally ate less and drank less. This allowed the organ systems to slowly shut down in preparation for death. Therefore, it follows that giving food and nutrition unnaturally can prolong the death process. If we are concerned about, as we say, "playing God" and making these decisions, we are actually doing it by giving fluid and nutrition in some instances and therefore prolonging death unnaturally.

Fluid and nutrition can cause increased discomfort for a dying patient by increasing respiratory secretions, coughing and shortness of breath, increasing GI

secretions causing nausea and vomiting for this patient, and it can also increase the peri-tumoral edema – the edema around the tumor – causing increased pain.

As for pain, nobody needs to die in pain – nobody. More cancer patients fear dying in pain than dying itself. Families of cancer patients consistently express the fear that their loved ones will die in pain. Almost every cancer patient, and I've taken care of hundreds, that I've ever seen, and their family, has expressed this fear to me. The same is true for my oncology colleagues across the country. Many people try to set out guidelines on pain. Leading pain researchers give the definition of pain as: "pain is whatever the patient says it is." And it should be treated appropriately so that the pain is alleviated. Cancer patients often need very large amounts of pain medication to relieve their pain, and as much as is needed should be given.

I will tell you another story about a friend who was dying from cancer down South. She had extreme pain. She was at home with hospice care. Hospice kept increasing her morphine to control the pain during her last few days. Finally the pain was controlled so that she was able to focus on her family, who had gathered, and even exchange intimate moments with her husband. They even joked about a few things. She was fully awake. She was getting over 300 milligrams (mg) of morphine an hour. That is a huge dose! Most people would expect it to cause instant death. It did not. Unfortunately the end of this story is not quite so peaceful. As death was imminent she became non-responsive. She was taken to the local hospital and seen in the emergency room. When they saw the amount of morphine that she was being given, they immediately dropped it to 20 mg an hour. She had extreme pain, was screaming in pain at the time of her death, begging her family to do something. The family is upset to this day about the experience. This should never have happened.

Pain medications are given in large amounts with the intention of alleviating pain. Narcotic medications do not have a therapeutic ceiling. Terminally ill patients do not become addicted. Alleviating pain is

not assisted suicide. It is pain control and at times will allow a patient to actually live a little longer with much improved quality time with their family. They can complete unfinished business with the family - and this is very important at the end of life - and they can die in peace. Adequate pain medication will allow a patient to breathe more easily, not stop breathing.

Every individual has a right to a peaceful death and society should insist on this right.

I also wanted to add two other things because of the questions that you raised. Ideally, everyone should have advance directives. Passing this bill will not guarantee that everybody is going to have those. So, the way I see it, when this bill passes - which I hope it does very quickly - it's not the end of our work. We need to follow up on that, get this well advertised, and get the message out so that people fill out their advance directives. When they're filled out, then we can act on them. To me, the passing of this bill is just the beginning of our work.

The other comment I have is that as far as other states and advance directives, I want to tell you that I have had my advance directives filled out for many years because of my many experiences. I keep a set in the safe at my parents house in New Jersey – both my husband and I – I also have a set of advance directives in my carry-on luggage that I take with me at all times, no matter where I'm traveling. I guess that's one of the hazards of being a nurse in this business.

CHAIR DYSON remarked that version U, which his office has helped to write, helps to clarify that regarding a comatose or incompetent pregnant woman patient, the presumption would be to preserve the life of the woman as long as possible to give the developing child as much time in the womb as possible to mature, thereby enhancing the chances of survival. He asked if this was standard practice in hospitals.

MS. EDWARDS replied that she has not worked extensively in ob/gyn but believed this to be true. She reported that ANA's board and legislative committee supports this issue, as does

she, saying “if there’s a chance of saving that child then we should definitely keep the mother alive on life-support or whatever it takes to allow that child to be born and survive. It would certainly comfort the family to have that child if they’re losing a member.”

CHAIR DYSON said this clarification has been done with the agreement of the bill’s sponsor. He stated he was irrevocably pro-life regarding the abortion issue, yet he was not aware that this was necessarily strengthening the pro-life position in the courts or in the debate. He said he thought one could deduce that this would be a wanted child if a woman had been carrying that child and had not previously elected the abortion option; it would be her and the family’s intention for that child to survive if at all possible. He acknowledged that the sponsor was nodding in agreement.

DR. WALLINGTON offered support of this issue, as well.

The committee took a brief at-ease at 2:18, at Senator Green's request.

MS. MARIE DARLIN, Coordinator for AARP Alaska Capital City Task Force, testified that after six years of working on this bill, AARP is glad that it has gotten this far. She referred to a letter of support from the AARP office indicating that “all states should have this type of legislation.” The aim has been to put a lot into one bill, to bring things up to date, and to address outdated legislation. She said considerable work has been done on this bill and attempts have been made to meet everyone’s concerns. She said that in the past three or four years, she has been involved with her own family’s situations and that different things happen at the time of death; what’s included in this bill would make all of that much easier.

MS. DARLIN told members that her sister passed away last spring after having cancer for several years and after losing her husband about one year prior to that due to a massive heart attack. Her sister, who had six children, and inoperable cancer, had completed the forms so that her children would know exactly how she wanted to be treated at the end of her life. Things went according to her wishes in a hospice situation, which really was the best. One month before she died, things were well taken care of and nobody had to worry about how things were going to be handled. Ms. Darlin then gave the example of her son-in-law, who had an inoperable brain tumor and had already verbally given instructions about how things were to be

handled. With the family knowing of his wishes, it was possible to do things "the best for him, right up until the very end."

MS. DARLIN continued that she lost a brother about two or three years ago who had not filled out any directives. He died of a massive heart attack while duck hunting - which was the joy of his life – and in that situation no decisions needed to be made. She said she has another elderly relative who is currently going through this process, whose kids want to know how to handle things. She [the relative] is planning to say - on her next trip to Fairbanks - "All right, now is the time, and we're going to make some decisions, and I'm going to make them." Ms. Darlin said that passing HB 25 would make this process easier because "all of it will be in one place."

CHAIR DYSON asked if she was familiar with version U, and requested that she circulate it to anyone wanting to have input.

MS. DARLIN replied that AARP remains supportive of HB 25, appreciates the work done by Representative Weyhrauch and his staff and will notify the committee if there are problems with the current version.

CHAIR DYSON asked if it was customary in other jurisdictions to have the actual document in the law rather than having the provisions in the law and the documents in regulation.

MS. EDWARDS replied she didn't know.

DR. WALLINGTON responded that she wasn't so familiar with other states.

MS. EDWARDS asked if people who already had their paperwork in order would have to make changes or if existing documents would be grandfathered-in.

REPRESENTATIVE WEYHRAUCH responded that statutory language is intended to cover the basics and that having forms different from those in statute would not be illegal. He said he'd have to get back to the committee to answer the question as to whether it's customary to have the documents included in the law.

CHAIR DYSON said he questioned the wisdom of including this and asked to be directed to the part of the bill clarifying that a specific document in the law doesn't have to be used, but can be modified or substituted.

MS. LINDA SYLVESTER, Staff to Representative Weyhrauch, referred to page 22, line 17, "Optional form. The following sample form may be used to create an advance health care directive ... this form may be modified to suit the needs of the person, or a completely different form may be used that contains the substance of the following form or otherwise complies with this chapter." She told members that one benefit of this statute is that it creates an optional form, whereas an impediment of current statute is that no options are available for the power of attorney and the living will.

CHAIR DYSON asked if the language was carefully crafted to make the directives clear and to avoid possible conflicts of litigation.

MS. SYLVESTER said a lot of work had been done on the language in the form, and that other states' options have been looked at, as well. As an example, she mentioned the situation of a family outside of the hospital room of a family member, trying to come up with ways to address the use of pain therapy.

TAPE 04-12, SIDE B

MS. SYLVESTER continued that there are several options available to the person who is expressing his/her attitudes toward pain medication and also towards artificial hydration and nutrition. One individual may desire that every option be exercised because of wanting to stay alive, while another individual might want the provision of artificial hydration and nutrition to allow time to determine what his/her recovery will be and to have the option to decide at a later point, when it seems like death is imminent. There are a number of scenarios and options in which attitudes can be expressed and conclusions can be drawn by surrogate decision-makers.

REPRESENTATIVE WEHRAUCH offered that the intent of the form is to make the directives as clear as possible and to avoid litigation and uncertainty at the end-of-life, although experience indicates that litigation will never be completely avoided. He said he would like to hear Dr. Wallington's response as to whether the form is clear enough.

DR. WALLINGTON said she had a lot to do with suggesting the wording, and directed the committee's attention to page 28, "artificial nutrition and hydration" and gave the example of a family struggling with this question prior to finding out that

there was a living will. The will revealed that artificial hydration and nutrition were not desired indefinitely. Knowing that a choice had been made was helpful and took a load off of the family.

CHAIR DYSON relayed that recently one of his staff had a parent who died; in this situation the woman was obviously terminal and almost never conscious and the continuing of food and water was producing great discomfort and a lot of complications. He said if a living will was executed by someone "not in the circumstance, and a long ways away from it", there ought to be a way for someone who previously said, "sure, keep giving me food and water" but after becoming incompetent, and from among those seeing the needless suffering being endured by someone who is dying and who is beyond being able to communicate, it seemed - "and I won't use the word torture" - but really inappropriate. His understanding was that the document before the committee makes the living will the guiding document and perhaps does not make it easy enough, in a case that is perhaps obvious, for that to be over-ruled. He asked Dr. Wallington to comment on this.

DR. WALLINGTON responded that this was an example of how "the world is gray and not black and white." She said it was interesting to hear the recognition of artificial nutrition and hydration as not being the end all and be all of existence. She said she has had a lot more difficulty with families being unwilling to give up artificial nutrition and hydration than recognizing that "they're doing bad things to people by using it." She said she would be open to suggestions regarding how to properly give an option for evaluating people's stated preferences, recognizing that perhaps it was not known what life would be like under those preferences and that perhaps a change is desired. She stated she didn't want to make it too easy to do away with what somebody has chosen because the point of the living will is to have one's choices followed. She brought up the difficulty with a person unfamiliar with the medical world who is making decisions based upon what he/she thinks is right, and then experiencing the consequence of that choice.

CHAIR DYSON alluded to the well-publicized case in Florida in which the patient was not in danger of dying from other causes but was questionably comatose and the husband, who had the authority to make the decisions, also had a vested financial interest in her dying sooner rather than later. He asked, "Is medical science capable with reasonable certainty of saying this person will never again be conscious and competent, or not?"

DR. WALLINGTON replied that there would be very few neurologists (the specialty making that decision) who wouldn't think that the statistics regarding their abilities firmly say that somebody, after a year, can have a very good sense of whether or not "they will wake up." She stated she had a different take on this particular case, remarking that she was "about 10 years out from" the incident and the chances of her changing would be miniscule. To answer the question, she said it was possible to make mistakes but there are very, very, very few [instances] when after a significant length of time, a person's status will change.

REPRESENTATIVE WEYHRAUCH referred to Chair Dyson's earlier comment about a person who is living, who has the authority to make decisions regarding someone else's healthcare and who would be the heir to assets when that other person dies, depending on the timing of the death. He said this was very common. He mentioned that when his own father passed away, the assets went to his mother, whereas if she had died first, her assets and the trust would have gone to his father. He asked if this was the type of scenario in question.

CHAIR DYSON responded that the situation he had in mind was, for example, that of the father and the oldest son both being terminal but still alive. If the father dies first, the estate goes to the eldest son and when he dies, the estate goes to the eldest son's children. However, if the eldest son dies first, the estate goes to the second child (a woman). In this situation, the eldest son's child was making the decisions for the grandfather.

REPRESENTATIVE WEHYRAUCH suggested that in those decisions, many factors go into analyzing the nature of the relationships: was it loving, close, continuous, supportive, adversarial; were there connections, hobbies, work projects; or was this a person who just interjected him/herself. He said that in these situations people can always repair to the courts for a determination but analyzing this goes to the fundamental issue of, "Where do we come from in adopting this kind of statute in our approach to these kinds of health care decisions?" Is it to continue life, or to make the person as comfortable as possible in death? And how to trust a person's decisions while he/she was conscious? "It's tough all around."

CHAIR DYSON said the following question has also come up: "If we do not have a living will directive and the agent or surrogate is making those decisions, should we have an appeal

process for other related adults to appeal the decision of the agent or the surrogate and have that appeals process such that it would work in a real time? You know, hours and days as opposed to months and years."

REPRESENTATIVE WEYHRAUCH responded that many of those cases become moot. He said they have to be in real time, or expedited, otherwise the factual basis for having the case dies.

CHAIR DYSON concurred, "Exactly right, and time might work for the bad guys, or it might work for the good guys." He suggested that in quite a few situations, one could go to a magistrate and get a stop order to buy some time to get the decision changed. He asked, "Do we have a remedy like that if this law passes?"

REPRESENTATIVE WEYHRAUCH said a remedy already exists. "You can always repair to the courts under this statutory scheme."

CHAIR DYSON asked if this was a readily available remedy.

REPRESENTATIVE WEYHRAUCH said, "Yes sir."

MS. SYLVESTER offered that currently there is a power of attorney for health care. In HB 25 this would be the agent, and there is the option of having a substitute agent as well. There is also guardianship and under current law one can nominate, through the courts, that guardian. The new law being brought in by HB 25 is the concept of a surrogate, somebody (such as a wife) who is the next logical candidate to make healthcare decisions; the hierarchy is laid out. If there is a disagreement and something is not right, a person or institution can bring the case to a higher authority. The public guardian is most likely assigned well in advance of an actual court hearing. Guardianship statutes in Alaska don't authorize that person to make decisions authorizing withdrawal of life-sustaining measures, so there's also that protection currently in place. Catholic Conference of Alaska suggests that if there is a disagreement, that the diverse opinions of the surrogates be considered by the healthcare provider before making a decision. Of course anybody in that group can take it to superior court and rectify the situation. She added that she didn't think the remedy would be as easy in a situation in which someone actually signed and was made an agent.

DR. WALLINGTON commented that if the healthcare provider community sensed that the decisions being pushed for were inappropriate, particularly in the realm of stopping care,

rights would be exercised under current law to ask for [guardianship]. It takes up to six weeks for the process of full guardianship to take place; temporary guardianship can be done rather quickly. The family can also exercise that right, it doesn't have to be the health system.

CHAIR DYSON said it appears that the law and the consent form assume that anatomical gifts will be exercised unless the person has explicitly declined wanting this. He asked if this was correct, and if this was the proper way to proceed.

DR. WALLINGTON said she had recalled that the agreement was that it was "inappropriate to have the process be one of [indisc.]."

REPRESENTATIVE WEYHRAUCH said the intent was, "You're not forced in at all. You have to opt in."

CHAIR DYSON clarified that this related to page 16, lines 14 - 17.

MS. SYLVESTER pointed out that there was a drafting error, and that updates had been submitted. She explained that [subsection] (k) was inadvertently included by the drafter. She said there was a change from the 1984 to the 1987 Uniform Anatomical Gift Act, except for a provision that would make Alaska an opt-out state. Alaska's new form has the option to reject this, which was not previously included. She mentioned that hospitals and hospital staff encourage and solicit organ donations, and approach family members to seek an opinion. That is currently law, and it will stay in.

CHAIR DYSON asked, "If a person had made an advance directive and opted out and said 'I don't want to be a donor' then the relatives or surrogates could not over-rule that?"

MS. SYLVESTER replied, "The decision's made by the principal and that's that."

CHAIR DYSON asked if in the absence of that - unless there's a record of desires clearly being made known - the agent or the surrogate could make that decision.

MS. SYLVESTER said, "Correct."

MR. CHIP WAGONER, representing the Alaska Catholic Conference, testified that the church remains as an advocate of the life and human dignity of every person. As stated by Cardinal Bernardin

of Chicago who has since died of cancer, the church supports that "seamless web of life from conception to natural death" and opposes mercy killing, assisted suicide, and euthanasia. He said that all statutes touching on this area of the law should have a strong presumption for life. ACC favors passage of HB 25 given that amendments are made; ACC will continue the good faith efforts in working with the sponsor, this committee and others to devise a bill that is worthy of having the word, "Alaska" at the top of it.

2:58 p.m.

MR. WAGONER expressed concern regarding the intent language and did not offer specific suggestions but said he would like to continue working with the sponsor to make improvements.

CHAIR DYSON mentioned that the intent language pertaining to the presumption of life is pretty good, but "is watered down in a couple of the sections further on."

MR. WAGONER concurred. He said with regard to an exception for mental health treatment for decisions by the surrogate, ACC thinks there should also be exceptions when abortion or sterilization decisions are made. That is, when there is nothing in the advance care directive by the principal; he referenced page 5, line 15. He said clarification is needed on page 6, line 8, subsection (d), dealing with individuals who have "exhibited special care and concern for the patient" because of the vagueness of the language. He said there is concern regarding some of the sections on "do not resuscitate" pertaining to someone who has made the decision of "do not resuscitate" to be able to withdraw that decision. He said this was for the principal but not for surrogates or possibly agents, and he wanted to ensure that "if someone says, 'do not resuscitate' that we have that."

MR. WAGONER continued that ACC is concerned about protocols that are not considered to be healthcare decisions. He said protocols seen in regulations deal with: 1) knowing who the patient is, and 2) having correct identification of that patient as a 'do not resuscitate' patient. He said there is nothing in the protocols indicating how to decide to not resuscitate. Those are all concerns. Mr. Wagoner remarked that it's been excellent working with the sponsor's staff and that many amendments have already been incorporated. He then referenced page 12, lines 17 - 24, which includes the language, "and other life-sustaining procedures" noting that ACC would like to see

that deleted. Mr. Wagoner stated concern with the language, "... to the extent prohibited by other statutes of this state" on page 13, line 27, subsection (f).

MR. WAGONER concluded that probably the most complex moral and legal issue is that of artificial nutrition and hydration. He distributed a statement from the United States Conference of Catholic Bishops [Nutrition and Hydration: Moral and Pastoral Reflections (1992)], and reiterated that this is just "not a black and white issue." He continued that ACC recommends that the best interest definition be slightly amended, and also that definitions of "qualified" and "terminally ill" be included. He then referred to artificial hydration and nutrition, suggesting that this belongs in a different category than most healthcare decisions because it results in death, and therefore should have a different standard than other healthcare decisions. He repeated that ACC supports the concept of HB 25 and hopes that work can get done this session so it can become law.

CHAIR DYSON said he wanted each committee member to indicate what questions remain to be answered before passing the bill out of committee.

SENATOR GREEN said she didn't have comments at this time.

SENATOR WILKEN said he was ready to move the bill.

SENATOR DAVIS said she wanted time to read and understand the suggested changes.

CHAIR DYSON suggested that Representative Weyhrauch's office work with his office to address concerns, resolve issues, and to isolate what cannot be resolved. After that, to circulate copies of the proposed solutions on these specific issues - including Mr. Wagoner's concerns - to committee members and to others who are interested. He asked if it seemed do-able to vote this out of committee at the end of next week.

REPRESENATIVE WEYHRAUCH concurred.

CHAIR DYSON said he thought there would be very few things that there wouldn't be closure on.

SENATOR WILKEN mentioned that next week's focus on POMV [Percent of Market Value] might affect scheduling.

CHAIR DYSON asked to be kept informed of scheduling conflicts.

MR. NOLAN then added to his previous testimony, saying he just received a copy of version U. He referred to the top of page 8, AS 13.52.045, and said, "pregnancy is back in here." He commented that [subsection] (c) does not apply to EMTs or to ambulance drivers when providing emergency services in the field. He suggested that under the definitions, a better phrase might be "health care providers" because depending on where one is in the state, a field emergency medical service may be performed by an emergency trauma technician, an EMT, a mobile intensive care paramedic, an RN, PA, or in some cases a physician. He said that under field conditions it can be extremely difficult to determine pregnancy, and even when determined, it is difficult to determine fetal viability. His suggestion was that "everybody gets covered."

MS. SYLVESTER said that consideration was being given to deleting everything after "does not apply to" and inserting "health care providers or emergency trauma technicians trained in accordance with AS 18.08.080 when providing emergency medical services." She said this would cover all of the emergency technician-type individuals in the field.

MR. NOLAN responded that he thought this language would work because under the definition of certified or licensed "health care provider," everyone is covered except for emergency trauma technicians.

SENATOR GREEN questioned if the language "in the field" would be included at the end of the sentence.

MS. SYLVESTER said she believed so because this would not be applied in a hospital setting.

Before adjournment, CHAIR DYSON said that during the meeting, the many good things said about Representative Weyhrauch and his staff had been understatements.

CHAIR DYSON held CSHB 25(JUD) in committee and adjourned the Senate Health, Education and Social Services Standing Committee at 3:10 p.m.