

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

April 14, 2004

1:41 p.m.

TAPE (S) 04 - 21&22

MEMBERS PRESENT

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

MEMBERS ABSENT

All members present

COMMITTEE CALENDAR

SENATE BILL NO. 383

"An Act relating to the Alaska children's trust grant awards."

MOVED SB 383 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

SENATE BILL NO. 376

"An Act relating to public assistance and subpoena powers."

BILL POSTPONED TO April 16, 2004

PREVIOUS COMMITTEE ACTION

BILL: SB 383

SHORT TITLE: CHILDREN'S TRUST GRANTS

SPONSOR(S): HEALTH, EDUCATION & SOCIAL SERVICES

03/31/04 (S) READ THE FIRST TIME - REFERRALS

03/31/04 (S) HES, FIN
04/14/04 (S) HES AT 1:30 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) HES AT 1:30 PM BUTROVICH 205
04/07/04 (S) -- Rescheduled to 5:30 pm 04/07/04 --
04/07/04 (S) HES AT 5:30 PM BUTROVICH 205
04/07/04 (S) -- Rescheduled from 1:30 04/07/04 --
04/14/04 (S) HES AT 1:30 PM BUTROVICH 205

BILL: SB 376

SHORT TITLE: PUBLIC ASSISTANCE AND SUBPOENA POWER

SPONSOR(s): HEALTH, EDUCATION & SOCIAL SERVICES

03/24/04 (S) READ THE FIRST TIME - REFERRALS
03/24/04 (S) HES, FIN
04/14/04 (S) HES AT 1:30 PM BUTROVICH 205

WITNESS REGISTER

MS. MARGO McCABE
Alaska Children's Trust (ACT)
Anchorage, Alaska
POSITION STATEMENT: Presented SB 383.

MS. KAYE SAXON
Alaska Children's Trust Board
Mat-Su Valley, Alaska
POSITION STATEMENT: Answered a question regarding SB 383.

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

MS. MARIE HELM
Christian Science Churches of Alaska
POSITION STATEMENT: Expressed concern that transferring to home
be included in HB 25.

MS. CAROLE EDWARDS
Alaska Nurses Association (ANA)
Juneau, Alaska
POSITION STATEMENT: Spoke to the issue of pregnancy in HB 25.

MR. JIM CARROLL
Juneau retired teachers
Juneau, Alaska
POSITION STATEMENT: Supports HB 25.

MS. MARIE DARLIN
Capital City Task Force of AARP
Juneau, Alaska
POSITION STATEMENT: Supports HB 25.

MS. EMILY NENON
American Cancer Society (ACS)
Anchorage, Alaska
POSITION STATEMENT: Spoke to the patient's right to control health care decisions, in HB 25.

MR. SAM TRIVETTE
Retired Public Employees of Alaska
Juneau, Alaska
POSITION STATEMENT: Supports HB 25.

MR. RAY VIDIC
POSITION STATEMENT: Encouraged passage of HB 25.

MS. LINDA SYLVESTER
Staff to Representative Weyhrauch
Alaska State Capitol
Juneau, AK 99801-1182
POSITION STATEMENT: Explained the proposed amendments to HB 25.

DR. MARIA WALLINGTON
Medical ethicist
Providence Alaska Medical Center
Anchorage, Alaska
POSITION STATEMENT: Answered questions pertaining to HB 25.

ACTION NARRATIVE

TAPE 04-21, SIDE A

CHAIR FRED DYSON called the Senate Health, Education and Social Services Standing Committee meeting to order at 1:41 p.m. Present at the call to order were Senators Green, Wilken, Davis, Guess, and Chair Dyson.

SB 383-CHILDREN'S TRUST GRANTS

The committee took up SB 383.

MS. MARGO McCABE, Alaska Children's Trust (ACT) Fund Board, testified from Anchorage and explained the four key provisions

in the bill. The first eliminates the \$50,000 cap that currently exists in granting awards to potential grantees seeking funds for programs eliminating child abuse and neglect in Alaska; the second requires that the project include a plan for self-sufficiency and program maintenance; the third limits funding to four years; the fourth allows the board to discontinue grant awards when outcomes are not being achieved.

SENATOR LYDA GREEN referenced page 2, line 10 that says, "75 percent of the first-year..." and asked where in the bill the \$50,000 cap was removed.

MS. McCABE confirmed that the \$50,000 provision is being repealed.

SENATOR GREEN asked if the whole section is being repealed.

CHAIR DYSON noted this was Section 2.

SENATOR GREEN asked why it's necessary to go from 50 to 75, and wondered if the intent is for the grant to become the sole support for this program, or if the project has energy of its own to create something that's being matched or added to.

MS. McCABE explained that one component is to eliminate the \$50,000 cap. Potential grantees can ask for a small size grant in the amount of perhaps \$5,000, or in an amount in excess of \$50,000. Second, it relates to self-sufficiency. The first year, a grantee can apply for funds to cover up to 75 percent of program costs; in the second year that amount can be 50 percent; in the third and fourth year that can be 25 percent. In addition, ACT is asking that there be a sustainability plan from the start in order to ensure that the entities have plans substantiating that the programs don't go away after the funding stops. This provides for greater flexibility in choosing the recipients of grant awards.

SENATOR GREEN asked what might be the maximum amount given to a single entity if there isn't a cap.

MS. McCABE said it varies in different states. The average grant across the country is about \$50,000. The current board favors continuing to fund the smaller grants. There are opportunities to fund larger programs, as seen in other states. She mentioned Missouri as recently having an average grant size of \$100,000 to 17 family-resource centers. She reiterated that

a maximum or minimum amount is not being proposed so that greater flexibility can be achieved.

SENATOR GRETCHEN GUESS confirmed that while this might be the intent of the current board, it sets a precedent so that there could be a grant for \$250,000 at some future time. That isn't the intent of the trust or statute, but it would be allowed with this change.

MS. McCABE responded that the current board's thinking "is not that" and that while concern regarding what future boards would do is necessary, this legislation would open the door for private foundations to give larger amounts of money that could then be turned around to larger programs. She said the board would have to exercise due diligence in making sure that the right amount of funds go to the programs most effective in combating this problem. She said the current board is capable of making such decisions, and she hopes the same will hold true with future boards.

SENATOR GREEN asked her to repeat what she said about private foundations.

MS. McCABE said, for example, if a private foundation chose to give \$100,000 but indicated that the money needed to be spent by the end of the year, or there was some condition on it, it would be hard to break that into smaller grants and turn it around quickly. This legislation would allow for the flexibility to issue a larger grant. She informed members that a \$600,000 appropriation could be coming to the fund in this cycle. The monies would have to be spent relatively soon - possibly by September - and the goal would be to spend the money on small community-based programs but also to invest in a media campaign or some other larger program that could help combat the problem of child abuse and neglect. She said that is just one example, and the hope is that over the next few years, part of the strategic planning process would be to attract larger sums of money from different entities including private foundations, and perhaps the federal government.

SENATOR GUESS asked if the current funding of the trust, besides fund raising, comes from interest payments from the principal that was invested somewhere in line with the permanent fund. She questioned whether \$600,000 could be deposited in the principal so that the board could use the interest from that to fund programs.

MS. McCABE said that wouldn't be possible in this particular case because the money is to be spent in this fiscal year, in the federal government's current appropriations cycle. She thought specific language in that particular allocation says it can't be added to principal, but needs to be spent on programs. She said it could be that future appropriations or donations from private trusts are not worded that way.

SENATOR WILKEN said he had three questions, and he began by asking whether the trustees support SB 383 because they are referred to obliquely in the sponsor statement.

MS. McCABE responded that the current board of the ACT fund supports the bill. The thinking is that it provides greater flexibility to the board in the grant-giving process, and allows for more responsiveness to community needs and allows for grants of all sizes. Particularly, the pieces that require the sustainability plan and the ability of the board to discontinue grants if objectives aren't met will help to ensure that monies are being spent appropriately on programs that will help to end this problem.

SENATOR WILKEN asked how the trust has interfaced with other funding sources, for example the Rasmussen Foundation. He said he was going to request a letter regarding another issue; perhaps the answer to that question could be included in the letter. He then asked how the Children's Trust money has been leveraged in the past to access other capital pools.

MS. McCABE asked if he wanted her to respond at this time.

SENATOR WILKEN said no, but that since SB 383 was going to Senate Finance, he would appreciate an answer at that time along with the letter having to do with the '05 grants. He expressed concern as to why the '05 grants haven't yet been designated. That was brought to his attention from folks in Fairbanks, he said. He wrote a letter to the commissioner about a month ago inquiring as to the status; he asked Ms. McCabe to follow up on that letter so that when the bill comes to Finance, she could provide him with an answer as to the status of the '05 grants, the intent of the department, and the answer to the leverage issue.

MS. McCABE agreed to do so.

SENATOR GREEN asked if the entire funding package of the Children's Trust goes through the regular process with the

capital budget or if it's possible to dispose of and award grants outside the legislative budget process.

SENATOR WILKEN said he believes it is outside of the budget process and it's not in the capital or operating budgets. He asked Ms. McCabe if this is correct.

MS. McCABE said the fund is a separate entity and that "we spend the net income of it."

SENATOR GREEN said she has seen a report for the year after it came back, so she would also like an updated report of what happened in the last two years.

SENATOR WILKEN asked if the status of grants in the last couple of years would be available.

MS. McCABE said absolutely, that the annual report was just prepared. She said she had the information available, but was happy to put it in letter format with additional detailed information on the grants for the Finance Committee.

SENATOR WILKEN said he would also pass that information on to people in Fairbanks who expressed the concern.

CHAIR DYSON noted Senator Wilken's presumption that SB 383 would pass out of committee today was probably true. He said if or when it gets to Finance, he would enjoy a list of the recipients. Since President Bush and Alaska's administration is so interested in involving the faith-based community in providing human services, he was particularly interested to see if the Children's Trust has involved folks from those communities, or not.

SENATOR GREEN asked if there were enough applicants to fill the \$600,000 request, or if they were not up to par.

MS. McCABE said unfortunately the money has not yet been received. If it comes, it would be in June or July because of delays in Congress in passing appropriation bills this past year. Because the fiscal year ends around September, those funds would need to be spent by then. In that 3-month period, an RFP would need to be submitted, and potential grantees would need to respond. There could be a lot of responses from different entities for smaller projects, and there would be support for those if they met the objectives. She expressed wanting to retain flexibility to work on some larger projects.

A media campaign is a very interesting project because it could heighten awareness of the problem, and provide a resource for people to turn to. She noted that Rebecca Parker reminded her that the media campaign could be used to leverage obtaining additional funds into the trust by promoting the trust itself, and making it known that contributions are accepted.

SENATOR GREEN asked if the \$600,000 is from federal dollars.

MS. McCABE said yes.

SENATOR GREEN said very often there is a waiver provision or an extension, and wondered if this was a possibility.

MS. McCABE said they would pursue that. The board didn't actively solicit these monies and they are trying to figure out how to work with and use them and make sure they are meeting the requirements if those funds materialize. In the next couple of years, the strategic plan includes becoming more proactive in looking for monies like this from private foundations and other entities. The board is trying to understand the process right now.

SENATOR GREEN asked, "Have you put the word on the street that this is a possibility?"

MS. McCABE said, "No, we haven't wanted to disseminate that information until we're sure it's going to be deposited in the fund."

SENATOR GUESS referred to Section 1, line 4, "the net income of the trust" and mentioned the use of the interest off of the trust. She asked why the \$600,000 couldn't go to the principal, but "that's not net income, that would be outside of that." She asked if the Children's Trust couldn't use that money for the media campaign because it has to award a grant to someone else for that media campaign, and that campaign has to have a self-sufficient proposal. If the grant comes through, she said she was confused whether the Children's Trust or a grant recipient would do that media campaign, and how such a large media campaign would be sustained over time.

MS. McCABE responded that the board hasn't decided where that money might go, but she thinks it would go toward small community-based grants as well as something like a media campaign. In current statute, there is some leeway in spending money to promote the fund. Also, there are other organizations

interested in this idea that could be a grant as well. Like the tobacco prevention campaign, which was an alliance of a number of different entities, and was funded in part through grant monies. It could go that route as well. She advised that they would meet on April 30 to review the current grant and to address some of these issues.

CHAIR DYSON agreed that Senator Guess's question regarding the language on page 1, line 4, "In awarding grants from the net income..." allows them to be a pass-through agency for grants authorized for other organizations. He said what the trust wants to do is probably fine, in general. He could argue that Senator Guess's concern could be better dealt with in Finance, so the bill could either be passed along to deal with that issue, or it could be set aside and addressed on Friday while the language gets fixed. He asked Senator Guess for she opinion.

SENATOR GUESS noted that neither she nor Senator Davis were on the Finance Committee.

SENATOR GREEN read from AS 37.14.200, "the principal of the trust consists of legislative appropriations to the trust and gifts, bequests, and contributions of cash or other assets from a person" and asked if the government could be considered as a "person" and said this implied that the contribution would go into the principal. This needs addressing, she said.

CHAIR DYSON asked Kaye Saxon if she would speak to this concern.

MS. KAYE SAXON, Alaska Children's Trust Board, testified from the Mat-Su and emphasized that removing the \$50,000 cap will allow flexibility regarding the monies they do have. She said there are many new trustees on the board who were trying to find their footing and determine parameters.

CHAIR DYSON suggested that Senator Guess was correct in assuming that the \$600,000 could not be used as a pass-through, so perhaps the trust board could propose an amendment that could be addressed in the Finance Committee.

SENATOR BETTYE DAVIS suggested this issue be dealt with in the Finance Committee.

CHAIR DYSON stated that Senator Guess raised an excellent question.

SENATOR DAVIS moved to report SB 383 out of committee with individual recommendations and the accompanying zero fiscal note(s).

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

2:15 p.m.

HB 25-HEALTHCARE SERVICES DIRECTIVES

The committee took up CSHB 25(JUD).

SENATOR GREEN moved version B [labeled 23-LS0137\B, Bannister, 4/6/04] as the working document.

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

REPRESENTATIVE BRUCE WEYHRAUCH said he wanted the record to reflect that he has worked with every possible interest on this bill, in good faith, and it is a very passionate, emotional, and very important bill. The Legislature must deal in a public policy arena with a broad spectrum of interests. He they have worked to ensure that one religion or another could not claim the bill. There is a higher duty to cross those gulfs if they exist.

CHAIR DYSON said Representative Weyhrauch preferred to take public testimony before addressing the amendments, which was fine with him. He informed members that he did not intend to pass the bill out of committee today.

MS. MARIE HELM of Christian Science Churches of Alaska testified via teleconference to reiterate the concerns she expressed at the April 7 meeting. She referred to version B, page 10, line 12 that speaks to transferring the patient. She asked that it clarify where the patient is being transferred because it's important that home be an accepted transfer point.

SENATOR GUESS noted that there is a significant difference between Versions B and V and then suggested to Chair Dyson and Representative Weyhrauch that this issue might be covered in Section G. Representative Weyhrauch acknowledged her point.

MS. CAROLE EDWARDS, Alaska Nurses Association (ANA), said she testified on this bill many times before, mostly about the

issues of pain and artificial fluid and nutrition. She said today she wanted to testify on the issue of pregnancy. She said she checked with a woman in her early 30s who is 8.5 months pregnant with her first child, and who has advance directives filled out. Upon being asked how she would feel about having her unborn child kept alive if something terrible happened to her, she said absolutely she would want this child kept alive. Ms. Edwards then asked her "if there were a statute that didn't provide for this, would you be hesitant to fill out advance directives?" She said yes she would. In fact she would rescind them if she thought that anything would happen to her in the next few weeks. Ms. Edwards pointed out that not including life support for pregnant women might deter young women from filling out their advance directives.

SENATOR GUESS said she didn't understand.

CHAIR DYSON explained that a person might fill out an advance directive indicating that "If I am irreversibly damaged and going to die and I'm comatose, withdraw the life support." If this person subsequently becomes pregnant and didn't think about rescinding that portion of the directive, she could get into the situation whereby her desire that the child live past her might not be fulfilled.

SENATOR GUESS expressed concern that someone could have a health directive that deals with pregnancy, and that directive could be over-turned by this statute. For example, if she directed that her husband make decisions, he should make those difficult decisions; "we shouldn't be over-turning a stated health care directive."

MS. EDWARDS asked if the statement "if I should become pregnant I would want to be kept alive for my child to be born" or something to that effect should be included.

SENATOR GUESS said that if pregnancy is included in this bill, it should be part of the health care directive or people won't know to address it. She also strongly suggested that if it is in the health care directive, "then we go by the health care directive. If there's not a health care directive, then we revert back to the statute. If there's a health care directive, I'm not sure why - and this is the only situation where we're trumping it - if the directive actually deals with pregnancy."

CHAIR DYSON said, "And we will get to that later on in the discussion. And it will be my perspective that if there's a

child there that we ought to do everything we can to preserve it and the state's interest in protecting that life trumps a directive. That's something we will disagree on, and we'll see how the committee feels."

MR. JIM CARROLL, representing Juneau retired teachers, referred to his own family situation and expressed support for HB 25, both personally and from having talked with other teachers.

MS. MARIE DARLIN, representing the Capital City Task Force of AARP Alaska, urged passage of this bill. She said it should be possible to get the bill through the Legislature this year since there's been four years of work put into it.

MS. EMILY NENON, Alaska advocacy manager for the American Cancer Society (ACS), emphasized that the legislation is critical to ensure that people's rights to be treated as intended are followed. In looking at the purpose and intent of version B, what caught ACS's attention in particular was the language, "It is the intent of this Act to establish the right of a patient to control the patient's own health care decisions." She said that ACS feels very strongly about that. Regarding the pregnancy issue - and she acknowledged that this would be addressed in the amendments - it was her hope and ACS's intention that people be able to make those decisions. If there is an advance health care directive, that "you be able to make what decisions you can in advance, but there are always going to be situations that we're not going to be able to perceive, and we feel very strongly that whoever is acting on behalf of a patient, if they are not able to act on their own behalf, be able to make those decisions as necessary, when things come up."

MS. NENON referred to the second stated intent of the Act on page 2, to "create, in the absence of evidence to the contrary, a presumption that the patient intends to be kept alive," which will cover people without advance health care directives. For people with advance health care directives, the desire is to ensure that they can decide what they want and, in their absence, that their loved ones and health care providers can make those decisions. She cautioned the committee to not legislate a line too fine to deal with situations as they come up. She mentioned her personal feelings due to her father whose living will was ignored three times over a number of years as he was dying from Parkinson's disease. Information was not properly transferred, and once a doctor did not acknowledge it. Statutes were not in place to clarify what it means to have an advance directive and living will.

SENATOR GREEN referred to her statement, "to keep it flexible enough" and asked if she had a particular word, line, or phrase in mind.

MS. NENON said she did not have an easy answer, and was interested in what was going on with the amendments. She commended Senator Guess's suggestion regarding including pregnancy as part of the advance directive form. She said she wanted to make sure that if somebody has an advance directive, or if they haven't addressed that specifically, that whoever is acting on their behalf is able to make those decisions. She said she wasn't a medical professional and the ACS doesn't get involved with the differences between being 1 week pregnant versus being 8 months pregnant, as those are very different situations and the medical care involved is very different. She reiterated that she wanted to make it clear that patients can make decisions about their health care and, if they can't, then their medical professionals and family can. She said the answer to the question was no.

SENATOR GREEN asked if the phrase "flexible enough" referred to the first paragraph at the top of page 2 or to the entire bill.

MS. NENON said, "I was saying that at the top of page two, that seemed pretty clear to me, that if you don't have an advance directive..."

TAPE 04-21, SIDE B

MS. NENON continued, "you've got this presumption and if you don't have somebody acting on your behalf, that's the fall-back position. But if we do have people acting on the patient's behalf, they need to be able to make those decisions."

SENATOR GREEN repeated that she wanted to clarify that Ms. Nenon's comment about flexibility referred to the entire process.

MS. NENON referred to the section on pregnancy on page 8, and to the importance of making sure that there's an opportunity for the people acting on behalf of a woman who's not able to act on her own behalf to make decisions as deemed necessary.

CHAIR DYSON said he inferred from Ms. Nenon's comments that in the example of a husband of a comatose and dying wife, the desire would be for him to be able to make the decision to pull

the plug on her life support even if that meant the death of the child that she wanted, the child that she hadn't chosen to abort.

MS. NENON said she understood what he was saying but "we're getting into dicey waters no matter which way you go on this." ACS's baseline position is stated in (1), under the Purpose and Intent, to "establish the right of a patient to control the patient's own health care decisions."

CHAIR DYSON said, "And by inference to allow their agent to do that if they're incapacitated." He said as he reads this legislation as it now stands, if there is an unborn child, the presumption is to preserve the life of that child and give it a chance to live.

MS. NENON said ACS does not have a position on abortion.

CHAIR DYSON said, "Abortion does not come into this. This is a wanted child. Do you want a third party to be able to make the decision to not give that child a chance to develop to the point that it can live outside the womb?"

MS. NENON said the statute was broad, and more clarity is needed to address situations involving different requirements when delivering a baby of a woman who is 39 weeks [pregnant] who was in a car accident versus a person who is 2 weeks pregnant regarding what might be required to sustain her life over that period of time. She said that's the distinction she makes in her mind, and the ACS goes back to "the patient should be able to control the patient's own health care decisions."

CHAIR DYSON mentioned sustaining that woman's physical life for another 25 weeks to give that child a chance to survive....

MS. NENON said she believes that decision should be made in conjunction with family members and medical professionals because of not knowing exactly what the situation will be.

CHAIR DYSON asked if this was ACS's position.

MS. NENON answered that ACS's position is the patient should be able to control his/her own health care decisions.

MR. SAM TRIVETTE, President of Retired Public Employees of Alaska, testified that the bill is much needed, and referred to his own parents dealing with end-of-life issues in the mid-

1990s. There was not an "advance directives bill" at that time. Fortunately several very caring doctors were able to meet his parents' wishes without advance directives. Had those caring physicians not been involved, things would have been a lot more difficult. He stated that having the bill is good public policy so that people will understand what's necessary in order to have advance directives. He said he'd like for this to not be an issue for his children when he is older. He acknowledged that Representative Weyhrauch and his staff have worked on this bill and compromises have been made over the past few years. He expressed support for the bill and for the amendments.

CHAIR DYSON acknowledged that Representative Weyhrauch and Linda Sylvester have done wonderful work.

MR. RAY VIDIC stated he was in favor of the bill and said he was testifying on behalf of the hundreds of people living in Alaska who can't be here because they need an organ, or for other health reasons. He shared a story about a friend who is the reason he is passionate about the importance of passing this bill. In the 10 years that his friend has been on dialysis, he has undergone self-dialysis 1,500 times and it has weakened his entire body. In the last two months when he was in Anchorage, he was bleeding rectally and needed a colonoscopy. Because his tissues were so weak, they poked through his intestine and he had to have surgery. Three weeks later he was healed and on his way home when his stitches broke from his breastbone to below his belly button, and he was back in the hospital again. He had an ileostomy and was back in Juneau; it was a mixed blessing because he didn't have to worry about some of the chemicals that he ingested because he didn't have an operable colon. "This gentleman is a warrior and he puts on his armor every day. Your legislation has the power to impact, not only my friend, but there are literally - and his direct circle of life, his family, his mother, father, brothers, cousins, uncles, aunts, friends - you have the opportunity through your decisions, he will receive a kidney, and he will have a new lease on life." Imagine that for one person who donates his/her body, there are 50 people who can benefit from that tissue and those organs, but that life touches many more; one donation impacts 1,000 people. He encouraged passage of HB 25.

CHAIR DYSON confirmed that this bill goes a long way to empower and enable organ transplants.

CHAIR DYSON moved Amendment 1 for purposes of discussion.

SENATOR GUESS objected.

MS. LINDA SYLVESTER, Staff to Representative Weyhrauch, explained the following [conceptual] amendments [in revised format, with corrected page numbers]:

(Conceptual) Amendment No. 1

13.52.000 To the uncodified law

Page 2, Lines 1 - 4
DELETE all.

Page 2, Line 1
INSERT:

(2) create, in the absence of evidence to the contrary, a presumption in favor of life, consistent with the best interest of the patient.
(3) this Act is not intended to condone, authorize, or approve mercy killing, assisted suicide, or euthanasia.

Amendment No. 2

13.52.010 Advance health care directives

Page 4, line 14

Delete: "if it complies with chapter."
INSERT: "to the extent that it complies with Alaska law."

Amendment No. 3

New Section Withholding or withdrawing of life-sustaining procedures.

Page 4, Lines 4-7
Delete all.

Page 7, Lines 10-13
Delete all.

Page 8, following Line 8

INSERT: Withholding or withdrawing of life-sustaining procedures.

(a) Notwithstanding any other provision of this chapter, an agent or surrogate may determine that life-sustaining procedures may be withheld or withdrawn from a patient with a qualifying condition when there is:

- (1) a durable power of attorney or other writing that clearly expresses the patient's intent that the procedures be withheld or withdrawn; or
- (2) no durable power of attorney or other writing that clearly expresses the patient's intent to the contrary, the patient has a qualifying condition as determined under AS 13.52.160, and withholding or withdrawing the procedures would be consistent with the patient's best interest.

Amendment No. 4

13.52.045 Decisions for exceptional procedures

Page 8, line 15

Delete: "physical"

Amendment No. 5

13.52.050 Pregnancy

Page 8, line 24

Delete: "health care"

INSERT: "life-sustaining procedures"

Page 8, line 25

Delete: "the health care"

INSERT: "life-sustaining procedures"

Page 8, line 28

Delete: "the health care"

INSERT: "life-sustaining procedures"

Amendment No. 6

New section: Construction where mental illness.

Insert a new section to read:

In the case of mental illness, nothing in this chapter may be construed to override or undermine the validity of a properly executed durable power of attorney.

Amendment No. 7a

13.52.300 Optional form

Page 30, Line 26

Delete all.

INSERT: I direct that adequate treatment be provided at all times for the sole purpose of the alleviation of pain or discomfort;

Amendment No. 7b

13.52.300 Optional form

Page 30, following line 30,

INSERT: "Should I become unconscious and I am pregnant, I direct that _____"

Amendment No. 8

Definition section.

We recommend a modified definition to "terminal condition" and we would then support the two circumstances for a qualified condition (permanent unconsciousness & terminal condition) rather than the three circumstances originally listed in version B (permanent unconsciousness, terminal condition **and incurable or irreversible condition**). Essentially, we have melded components of incurable or irreversible condition into terminal condition.

(35) "qualifying condition" means a terminal condition or permanent unconsciousness in a patient.

Terminal condition becomes its own definition rather than a component of "qualifying condition"

Terminal condition: a new definition is added to the Definition section:

() Terminal condition means an incurable or irreversible illness or injury that without administration of life sustaining procedures will result in death in a short period of time; for which there is no reasonable prospect of cure or recovery; that imposes severe pain or otherwise imposes an inhumane burden on the patient; and for which initiating or continuing life-sustaining procedures in light of the patient's medical condition, provides only minimal medical benefit.

Life-sustaining procedures is amended by adding a new phrase (underlined in body of the definition).

(27) Life-sustaining procedures means any medical treatment, procedure, or intervention that, in the judgment of the primary physician, when applied to a patient with a qualifying condition, would not be effective to remove the qualifying condition, would serve only to prolong the dying process, or, when administered to a patient with a condition of permanent unconsciousness, may keep the patient alive but is not expected to restore consciousness; in this paragraph, "medical treatment, procedure or intervention" includes assisted ventilation, renal dialysis, surgical procedures, blood transfusions, and the administration of drugs, including antibiotics, or artificial hydration and nutrition."

MS. SYLVESTER explained that in Amendment 1, the language in "(2)" covers the balancing act. Once the decision-maker is on the scene, that person will be making those decisions, always considering the best interests of the patient. That means that the burdens of a health care decision are weighed against the benefits. She confirmed that "(3)" states that the intent is not to condone mercy killing, assisted suicide, or euthanasia.

REPRESENTATIVE WEYHRAUCH referred to Ms. Nenon's concept of a "fine line" as being important to keep in mind because of there being so many possible situations. He reminded members that in talking about policy determination, ultimately it's the patient, their agent, family, and the physicians who have to make these decisions, and they are made on a case-by-case basis. It's impossible to dictate in statute what to do or not do in these

emotional, medical, personal, family, and social situations. It's inappropriate to have to look for legislative intent while dealing with somebody in a critical care unit, at home, or in hospice.

SENATOR GUESS read from [page 2, line 2], "until given the opportunity to make health care decisions directly or through an agent, a surrogate, or a guardian" and asked, given that everything goes back to best interest of the patient, why was this being deleted?

MS. SYLVESTER explained that Amendment 1 is a compromise. She said imagine a situation in which someone comes in after an accident; the presumption is that the patient wants to be kept alive, we err on the side of life. Current medical practice does not wait around to discover what the patient wanted. Action is taken to stabilize the patient. After that, data is gathered about the patient's physical condition, the prognosis, and the patient's health. A decision-maker comes to the scene. The concern is that this language would put the presumption in favor of life over the patient's individual decision-making. That was a concern in the Nancy Cruzan case, for example. The reason the guardian kept pushing the case further was because Missouri had a presumption in favor of life that was so strong in the living will statute, that her dire, desperate, physical condition was not enough to trump that presumption in favor of life. Having said that, the individual analysis that will occur during the best interest - making a decision as to what's in the best interest of this patient - envisions decision-making by others (medical, family, or loved ones).

SENATOR GUESS said the way it currently reads, best interest trumps the decision of an agent, surrogate, or guardian. She said she might be someone who says:

You better do everything that you can do, and my husband gets to the emergency room, and the people say, 'well it's best interest' which is kind of this cost-benefit, all this other stuff, and I as the agent or the spouse don't get to make that decision because this is saying that the best interest trumps versus the agent, and the best interest is clear but it's not clear. They're great guidelines, it's well-written, but you can have it switch the other way and not be too heavy in the presumption of life but actually take away someone who wanted that strong presumption of life. Am I correct?

MS. SYLVESTER said this amendment was offered by Chair Dyson and, from Representative Weyhrauch's point of view, the original language was preferable, but it's negotiable, as there were other battles that they felt more strongly about.

SENATOR GUESS said to Chair Dyson, there's an unintended consequence here and wondered if that was what he was intending.

CHAIR DYSON said he thought it was. He asked if somebody could speak to what goes into the best interest determination for a patient.

2:52 p.m.

DR. MARIA WALLINGTON, medical ethicist at Providence Alaska Medical Center, testified via teleconference, saying that the decision needs to be made between physicians who can offer information regarding the realities of the medical situation and the family, who knows that patient's values. She referred to page 37, noting that at the end of the list under what's included in the definition of "best interest" is: "(G) the religious beliefs and basic values of the individual receiving treatment." She said at the time the best interest is being determined, one wants to include all of the medical realities and information about the patient, which is provided by the surrogate. She said she didn't think that taking it out adds anything and that keeping it in makes it clearer, saying that she agrees with Senator Guess on this point. She said she was not willing to fight for it because in the rest of the bill, the way surrogates have been set up along with the definition of best interest recaptures that part.

CHAIR DYSON said that in the absence of evidence to the contrary, like an advance directive, the presumption is to preserve life, consistent with the best interest. People go through this "best interest" list to do the best they can in the absence of an advance directive, or evidence to the contrary, to decide what's best for that patient.

SENATOR GUESS said she wouldn't maintain her objection, but said it needs to be re-thought. She referenced page 38, line 4, and said that "religious beliefs and basic values" could be trumped by the medical situation. With making that point, she withdrew her objection.

CHAIR DYSON announced Amendment 1 was adopted.

CHAIR DYSON moved Amendment 2.

MS. SYLVESTER explained that there is concern with states adopting statutes that offend the sensibility of other states. Alaska, among other states, is re-thinking reciprocity.

SENATOR GUESS noted that the correct page number for Amendment 2 is page 4, line 14 [rather than page 5, line 7].

MS. SYLVESTER continued by explaining that it is important that Alaska honor advance directives, living wills, and anatomical gift donations signed by people from out of state. If someone is visiting Alaska, those directives need to be honored to the extent that they comply with Alaska law. If, for example, someone is from Oregon, which authorizes assisted suicide, the desire is to make it clear that those wishes won't be carried out in Alaska because it doesn't comply with Alaska law.

CHAIR DYSON asked if a similar change needed to be made to page 12, lines 26 - 27.

MS. SYLVESTER responded no, that it has been corrected regarding anatomical gifts and the "do not resuscitate" orders.

CHAIR DYSON confirmed that she had just said that page 12, lines 26 - 27, version B was fine as is. He then asked if the language was also fine on page 22, lines 18 - 20.

MS. SYLVESTER said that is correct, and explained that the language on page 22 describes the exemption from liability for the anatomical gift, and says that with regard to a physician or Life Alaska acting on someone's anatomical gift donation made in another state, the desire is to prevent liability for acting on that.

CHAIR DYSON acknowledged that there was no objection to Amendment 2. He moved that Amendment 2 be amended to correct the page number of page 4, line 14. He then asked if there was any further objection. There being none, Amendment 2 was adopted.

CHAIR DYSON then asked Ms. Sylvester to address Amendment 3.

MS. SYLVESTER said this was a substantive change and explained [using herself as an example] that regarding health care decisions, she makes them for herself because she's a thinking person who's awake; she's not unconscious. If she became

unconscious and lost capacity, someone else would make those decisions. If she filled out an advance health care directive, then she'd have an agent (name somebody). If she were part of the 90 percent of the population who have never filled out an advance directive, then HB 25 creates a new group of people called health care surrogates. This would be her husband, for example, or if he was not available, her mother (someone close, who would know of her wishes). Those people are making health care decisions.

MS. SYLVESTER continued that if, for example she were unconscious and needed to have her leg fixed after a car accident - it could be trivial decisions that need to be made until regaining capacity - but these people may also find themselves in circumstances in which they're making decisions to withdraw or withhold life support. It's in the interest of the state to put some parameters around that decision-making process. Withdrawing life support is not the same as consenting to have a spleen removed, for example. For her husband to make those decisions, she has to have a qualifying condition. She has to be in a persistent vegetative state, for example, or be terminally ill, unconscious, in the advance stages of cancer and dying, if someone is going to decide to withhold or withdraw artificial hydration, or just let her die. That's an example of those parameters.

MS. SYLVESTER said the agent and surrogate are dealt with separately in version B. Chair Dyson wanted to highlight the importance of this by giving the withholding or withdrawing of life-sustaining procedures a separate section. Ms. Sylvester referenced the suggested changes included in Amendment 3. She explained that these changes eliminate from the equation a husband who gets into a serious motorcycle accident or a burn victim who is burned but will recover - those people would not have a qualifying condition - so therefore it would be inappropriate and not allowed under this law to withhold or withdraw life-sustaining procedures. That's how to ensure that Alaska is not allowing euthanasia or mercy killing or anything like assisted suicide.

CHAIR DYSON moved Amendment 3.

DR. WALLINGTON pointed out that the correct reference is page 7, lines 10-13 [rather than lines 4-9].

MS. SYLVESTER suggested that these be considered as conceptual amendments [because of the reference modifications].

CHAIR DYSON then moved conceptual Amendment 3.

SENATOR GREEN asked if the new section being added to Amendment 3 was the first mention of "durable power of attorney" or if it occurred throughout the bill.

MS. SYLVESTER said regarding consistency, it started out with a living person, anticipating, "I'm an individual" and when an advance directive is filled out, "I'm a principal" but later on, the same person (me, as the individual with the advance directive), may become a patient, so it tracks accordingly.

REPRESENTATIVE WEYHRAUCH clarified that the question was where, in the bill, the terminology appears.

SENATOR GREEN said she wanted to be sure it was consistent, as she doesn't remember seeing it that often.

CHAIR DYSON then announced and apologized that SB 376 would not be heard that day.

CHAIR DYSON asked if there was any objection to Amendment 3 as amended.

DR. WALLINGTON said she wanted to comment on the terminology, noting that most of the bill uses "health care agent" rather than "durable power of attorney."

MS. SYLVESTER responded that regarding this issue she needs to look through the bill for conformity because various people have given input at various stages.

CHAIR DYSON said seeing and hearing no objection to Amendment 3, Amendment 3 is adopted.

CHAIR DYSON moved Amendment 4.

SENATOR GUESS objected and noted that the correct page reference is page 8, line 15.

MS. SYLVESTER explained that this amendment deals with a protection that comes from the guardianship statute, and is important to folks with mental illness. Unless there is a durable power of attorney for health care or another written document clearly expressing an individual's intent to the contrary, an agent or surrogate may not consent on behalf of the

patient to an abortion, sterilization, psychosurgery, or removal of bodily organs except when the abortion, sterilization, psychosurgery, or removal of bodily organs is necessary to preserve the life of the patient or to prevent serious impairment to the health of the patient. If someone is mentally ill, sterilization was formerly a standard order. If it's necessary to prevent harm to the patient's physical health, then there's an option. Because psychosurgery deals with mental health, the word "physical" needs to be deleted.

CHAIR DYSON asked if the objection was maintained.

SENATOR GUESS said no.

CHAIR DYSON announced that with the withdrawal of the objection, Amendment 4 was adopted.

3:15 p.m.

CHAIR DYSON moved Amendment 5.

SENATOR GREEN objected for purposes of discussion, and pointed out that the correct page number is page 8 rather than 9.

MS. SYLVESTER explained that this section comes from current statute, and it is the "do not resuscitate orders (DNR)" and the living will statute. It is one of the statutes being repealed and re-implemented in HB 25. She said this was expanded to include advance health care directives, but because it created confusion, we're essentially backing-up. Before implementing a health care decision for a woman of childbearing age that would affect a fetus, if present, the supervising health care provider shall take reasonable steps to determine whether a woman is pregnant. That is standard practice and is not new, as women of this age are routinely checked for pregnancy.

MS. SYLVESTER referred to "(b) Notwithstanding any other provision of this chapter to the contrary, an advance health care directive by a patient or a decision by the person then authorized to make health care decisions for a patient may not be given effect if" certain conditions are present. The patient is a woman who is pregnant and is unconscious, lacks capacity, and most typically she will be unconscious. The directive is a decision to withhold or withdraw health care but what it really meant is life-sustaining measures. We don't mean health care, for we don't mean to imply that if a woman is in a car accident and is going to recover, but the treatment is going to harm the

fetus, the implication is not to put the life of the fetus ahead of the life of the mother. Amendment 4 removes health care and puts in life-sustaining procedures.

MS. SYLVESTER continued that the withdrawal or withholding of health care - and health care needs to be changed to life-sustaining procedures - would, in reasonable medical judgment, be likely to result in the death of the patient. It's clear from reading this that the woman is dying or is near death. It could be a DNR, she could have already died and they resuscitated her. The last condition to be met is that it is probable that the fetus could develop to the point of live birth, if life-sustaining procedures were provided. This section of the bill is worded flexibly so that it allows for discussion and decision-making, but the probability is that the fetus could develop to the point of live birth. If the woman is eight months pregnant, it's probable. If the mother is dying, the removal of life support is stayed, to give the fetus the opportunity to live. This is standard practice. In some cases, doctors consider whether there are one or two patients.

CHAIR DYSON clarified that conceptual Amendment 5 deletes "health care" and inserts "life-sustaining procedures" on page 8, line 24; page 8, line 25; and page 8, line 28.

CHAIR DYSON asked if there was any objection. Seeing none, Amendment 5 was adopted.

CHAIR DYSON moved Amendment 6.

MS. SYLVESTER said this was first proposed by the Disability Law Center and was incorporated into the working draft, version X. She said that in the case of mental illness, nothing in this chapter overrides or undermines the validity of a properly executed durable power of attorney. The real world scenario that the Disability Law Center is concerned about is that someone who is in API loses capacity or is incompetent.

CHAIR DYSON asked if there was any objection.

SENATOR GREEN asked about the amendment's location on page 13, line 29.

MS. SYLVESTER said the drafter could put it anywhere.

SENATOR GREEN said it is currently located between (a) and (b), and wondered if this was desired.

MS. SYLVESTER said this could be considered as a conceptual amendment and could go wherever the drafter would like to find a space for it.

CHAIR DYSON agreed that it could go where the drafter feels it is most appropriate. He asked if there was any objection. There being none, Amendment 6 was adopted.

CHAIR DYSON moved conceptual Amendment 7.

SENATOR DAVIS objected.

MS. SYLVESTER said there were a couple of suggested changes to the optional form. There was discussion about the actual wording in [Relief from Pain], with the concern that someone not be thinking about terminating life with pain relief, countered with not lecturing to the patient or creating confusion about pain medication. What was arrived at, which is a nice compromise, is "I direct that adequate treatment be provided at all times for the sole purpose of the alleviation of pain or discomfort;".

TAPE 04-22, SIDE A

SENATOR GREEN asked if "or" was being omitted, to be followed by instructions.

MS. SYLVESTER referred to page 30, line 25 of version B, and said that Relief from Pain, lines 26 - 28, were being taken out.

REPRESENTATIVE WEYHRAUCH noted that "or" stays in.

CHAIR DYSON confirmed the new language would be on page 30, line 26, and asked if the desire is to expand Amendment 7.

MS. SYLVESTER confirmed something should be included in the Optional form, after Relief from Pain. She explained this would be a conceptual amendment and would still need to be worked out with Senator Guess, Chair Dyson, and Doctor Wallington. This would provide an option to discuss a person's attitudes and directives regarding the situation of pregnancy.

CHAIR DYSON asked for Amendment 7 to be adopted.

SENATOR WILKEN suggested that this be called Amendment 7a, and the other, Amendment 7b.

CHAIR DYSON announced that Amendment 7a was adopted.

MS. SYLVESTER said the language for Amendment 7b would essentially be, "Should I become unconscious and I am pregnant, I direct that" and would be followed on page 31, by Other Wishes.

SENATOR DAVIS moved conceptual Amendment 7b.

CHAIR DYSON objected, and asked Ms. Sylvester to review the amendment.

MS. SYLVESTER said it would come after [Relief from Pain] and before Other Wishes. The idea is that the form is designed to have people encounter or confront these decisions. For example, one concern expressed to me was, "If I'm in a situation where it's my life or my child, I want my child's life to come before my own." This would provide an opportunity for someone to state those wishes. They could be stated in other wishes, but without having an option for pregnancy, it might not occur to the person who is filling out the form. The idea is not to trump the presumption in favor of life, or what we worked on in pregnancy. Senator Guess has her concerns, but it was actually suggested for people who want to be clear that they want their child's life to come before their own.

SENATOR WILKEN asked if 7b would insert paragraph (E) on page 30.

MS. SYLVESTER said she thought it would become a new "(7)."

SENATOR WILKEN asked if Other Wishes would become "(8)."

MS. SYLVESTER replied correct.

SENATOR GUESS asked if the objection was maintained. She stated for the record that she has issues with the pregnancy section because it overturns the health care directive. Regardless if it is included or not, she said she thought it was extremely important to have it in the health care directive so that those conversations happen. Most likely, most people will make the decision to do everything possible to save the child, but if that's not in the health care directive, you get into some fairly murky water. It might be better to deal with pregnancy in best interests, but it's not addressed in best interests. She said it doesn't hurt to prompt people to have those

conversations, since "not everyone gets to sit in committee rooms and know that they should have them."

DR. WALLINGTON said she supports this, and the major value of putting an optional form into the law itself is that it will prompt people to think about important decisions.

MS. SYLVESTER re-stated the proposed conceptual Amendment 7b for clarification.

CHAIR DYSON removed his objection.

CHAIR DYSON asked if there was further objection. Seeing none, conceptual Amendment 7b was adopted.

CHAIR DYSON moved to adopt Amendment 8.

SENATOR WILKEN objected.

MS. SYLVESTER explained that version B discusses three qualifying conditions. These are situations in which the decision-maker may consider withholding or withdrawing life-sustaining procedures. One of the conditions is a state of permanent unconsciousness. The other is a terminal condition, and the third, an incurable or irreversible condition. We've merged terminal condition and incurable condition and called this terminal condition. That was a compromise that was worked out with Chip Wagoner from [Alaska Catholic Conference], and is supported by Dr. Wallington as well. Regarding "life-sustaining procedures" Chair Dyson's language that appeared in version X has been adopted into the definition. The definition section deals with three definitions: qualifying condition, terminal condition, and life-sustaining procedures. She noted that this could be considered as a conceptual amendment.

CHAIR DYSON asked if the objection was maintained.

SENATOR WILKEN said no.

CHAIR DYSON announced that Amendment 8 was accepted.

MS. SYLVESTER asked for leeway from the committee so that the bill could be reviewed for inconsistencies, brought to the drafter's attention and fixed. [The request was treated as accepted.]

CHAIR DYSON noted for the record that there was a slight question about judicial relief on page 15, and the definition of cardiopulmonary resuscitation on pages 10 and 11.

SENATOR GUESS asked, for the record, if there would be time to work through some issues with Ms. Sylvester.

CHAIR DYSON responded in the affirmative.

SENATOR WILKEN asked about passage of HCR 31, and received confirmation that this had passed out of committee.

CSHB 25(JUD) was held in committee.

There being no further business to come before the committee, Chair Dyson adjourned the meeting at 3:32 p.m.