

SB 177

SENATE FINANCE COMMITTEE REPORT

DATE: 3/13/91

FURTHER:

DATE TURNED
INTO OFFICE:

4/3/91

The Finance Committee considered SENATE BILL NO. 177

"An Act making a special appropriation to the Department of Health and Social Services for payment as a grant to Blood Bank of Alaska, Inc.; and providing for an effective date."

and recommended:

- replace with _____ CS _____
 - or adopt _____ CS _____
 - attached amendment(s)
 - _____ letter of intent adopted
- same title
 - new title
 - technical title change (HB only)

do pass

do not pass

no recommendation

individual recommendations

further referral to _____

ATTACHES NEW FISCAL NOTE(S):

Dept/Date:

fiscal note(s) _____

zero fiscal note(s) _____

APPROVES PREVIOUS:

Dept/Date:

fiscal note(s) _____

zero fiscal note(s) _____

appropriation-no fiscal note

SIGNING DO PASS:

OTHER RECOMMENDATIONS:

Jim Duncan

Al Adams

Lynda Hoffman

Dick Stutz No Rec

1. J. H. ...

2. K. ... Do pass

Co-Chairs: Signatures and Recommendations

SENATE BILL NO. 177

IN THE LEGISLATURE OF THE STATE OF ALASKA

SEVENTEENTH LEGISLATURE - FIRST SESSION

BY SENATORS COTTEN, Halford, Menard, Uehling, Collins

Introduced: 3/6/91
 Referred: HES and Finance
 Funding Information: General Fund \$222,000
 Other Funds -0-
 \$222,000

A BILL

FOR AN ACT ENTITLED

1 "An Act making a special appropriation to the Department of Health and Social Services
 2 for payment as a grant to Blood Bank of Alaska, Inc.; and providing for an effective
 3 date."

4 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:

5 * Section 1. The sum of \$222,000 is appropriated from the general fund to the Department of Health
 6 and Social Services for payment as a grant under AS 37.05.316 to the Blood Bank of Alaska, Inc., to
 7 assist it in increasing the enrollment of Alaskans as bone marrow donors in the national bone marrow
 8 donor registry during the fiscal year ending June 30, 1992.

9 * Sec. 2. This Act takes effect July 1, 1991.



Alaska State Legislature

SENATE

Official Business

P.O. Box V
State Capitol
Juneau, Alaska 99811

MEMORANDUM

TO: Senator Pat Pourchot
Co-Chairman, Senate Finance Committee

FROM: Senator Sam Cotten *SC*

DATE: March 12, 1991

RE: SB 177 - appropriation for Blood Bank of Alaska

During the Senate HESS Committee hearing this morning, the committee passed out the captioned bill and its companion measure (SCR 17 - Bone Marrow Donor Week). I would appreciate it if you would schedule Senate Bill 177 for an early hearing.

Attached is an information packet regarding the bill and the companion measure, SCR 17 (which will now go to Rules).

SB 177 requests an appropriation of \$222,000 as a grant to the Blood Bank of Alaska to assist in increasing enrollment of bone marrow donors in Alaska. If you have any questions, please do not hesitate to contact me or Bill Stoltze, my staff person working on this legislation, at 3711. Thank you for your assistance.

Attachment

2

BLOOD BANK OF ALASKA, INC.
REQUEST FOR STATE OF ALASKA FUNDING

The Blood Bank of Alaska, Inc., is a not-for-profit corporation serving the blood needs of Alaskans for over 29 years. A year and one-half ago, the Blood Bank of Alaska became the only Alaskan recruitment center for the National Bone Marrow Donor Program (NMDP). The following explains the purpose and need of the NMDP and the Blood Bank of Alaska.

- o There are close to 10,000 patients nationwide with leukemia and other related blood diseases who cannot find a donor and will not survive without a bone marrow transplant. One in 6,000 children alone will be diagnosed with fatal childhood leukemia. The diseases are not thought to be inherited and can happen to anyone, any age, anytime. Alaskans and thousands of others have already died for lack of a "miracle match" marrow donor. All of these numbers increase daily as new cases are diagnosed and time runs out for those who are searching for a matched donor.

For a transplant to be successful, the donor and the patient must have the same immune system recognition signals, called Human Leukocyte Antigens or HLA. To be a perfect match, all six HLA locations on the donor's white blood cells must be identical to the patients. The odds that two unrelated individuals will match is one in 20,000.

- o The NMDP was created to establish a national registry of individuals who could donate marrow to unrelated patients. The more donors enrolled into the registry, the greater the chance a patient has of finding a match.

The Blood Bank of Alaska has received numerous requests from groups and individuals throughout Alaska who are interested in enrolling into the NMDP Registry. As a combined effort, we can offer hope and life to thousands of people suffering from fatal, but now curable, leukemias and other blood related diseases.

The Blood Bank of Alaska is requesting funding from the State of Alaska in the amount of \$222,000 in support of enrolling an additional 3,000 marrow donors into the national registry.

Additional Expense for Remote Locations	SUBTOTAL	\$ 36,300
		<hr/>
	TOTAL EXPENSES:	\$ 221,800

ANNUAL

5. OTHER EXPENSES

Shipping (Federal Express Overnight Delivery Service); 32 specimens/shipment (4 boxes together) X 2600 donors, plus 50 individual shipments for additional testing	\$ 6,600
Telephone/FAX Charges; long distance calls re: shipping information to lab, FAXing HLA data for enrollment in registry, miscellaneous related calls	225
Printing (excluding information packages); handouts to potential donors concerning future draw sites, miscellaneous information for donors	300
Miscellaneous; donor acknowledgements, etc.	150
	<hr/>
TOTAL OTHER	\$ 7,570

		<u>ANNUAL</u>
<u>3. EQUIPMENT</u>		
(One Time Purchase)		
Fireproof Locking File Cabinet	\$	800
4 Each Blood Pressure Cuffs		300
Off-Site Phlebotomy Carrying Cases		275
		<hr/>
TOTAL EQUIPMENT	\$	1,375

4. SUPPLIES

Medical Supplies For Enrollment (test tubes, needles, gauze, etc.); \$1.55 per sample X 2600 donors plus additional supplies for further typing (50/Yr.)	\$	4,100
D.O.T. Approved Specimen Shipping Containers (double-insulated, foam-lined, plastic barrier); 8 specimens/box @ \$4.40 X 325 donors, plus separate individual box for additional specimen for DR and MLC test (50/Yr.)		1,650
HLA Typing Charge (performed by NBMP-certified lab (Alaska does not have an in-state HLA Lab); \$50 X 2600 donors		130,000
Office Supplies (files, labels, envelopes, etc.); 15 cents/donor, plus \$300 in xerox paper		700
Postage (mailing information/consent package = 75 cents/each; enrollment letter = 29 cents/each) X 2600 donors, plus miscellaneous correspondence of \$100		2,700
Infectious Disease Marker Testing (performed only on potential donor when additional HLA typing requested); 50 X \$28 (portion not reimbursed by NBMP)		1,400
Information Package (contains Q & A, consent form, medical history, donor data sheet, cover letter); copying charge X 54 cents/each X 2600 donors		1,400
		<hr/>
TOTAL SUPPLIES		\$141,950

APPENDIX 1

Additional Expenses For Enrollment of Donors
at Remote Locations

The following additional expenses are for the recruitment of donors at six remote locations. The figures are based on the following assumptions:

- o All coordinating site selection and organization for remote draws is done from Anchorage.
- o Volunteers are available at the remote site to coordinate activities and times.
- o A facility in which to perform information sessions and collect specimens is provided for BBA to use (a hospital room, school room, fire station, or office building).
- o The location of the site is no greater than two hours air travel time distant; and a roundtrip can be made in one working day (no overnight trips).
- o A minimum of 50 residents are interested in enrolling in the program, with a maximum of 100 per day.
- o A hospital, lab, clinic, or physician's office in the community is willing to draw any future specimens needed for additional HLA typing on a specific donor.

PERSONNEL

<u>Technical Coordinator:</u>	16 Hrs. Coordinating/Site; 12 Hrs. At Each Site; 6 Sites - 168 Hrs. X 19.50 + 23% Fringe Benefits	\$ 4,040
<u>Clerical:</u>	12 Hrs./Site X 6 Sites - 72 Hrs. X \$9.50 + 23% Fringe Benefits	850
<u>Phlebotomist:</u>	12 Hrs./Site X 6 Sites - 72 Hrs. X \$13 + 23% Fringe Benefits	1,160
		<hr/>
	ADD'L PERSONNEL EXPENSE	\$ 6,050

TRAVEL

2 Each Roundtrip Tickets, Coach; Average \$333/Ticket X 2
Tickets/Site X 6 Sites

ADD'T'L TRAVEL EXPENSE \$ 4,000

SUPPLIES

\$55.40 Per Donor X 450 (includes HLA typing charge)

ADD'T'L SUPPLIES EXPENSE 24,950

TELEPHONE/FAX

ADD'T'L TELEPHONE/FAX EXPENSE 500

SHIPPING SPECIMENS TO BBA

ADD'T'L SHIPPING EXPENSES 300

TOTAL ADDITIONAL EXPENSES \$ 36,300

Doris Moody never believed she'd be called, let alone chosen, when she signed up as a bone marrow donor last May.

"It's always a nice thought in the back of your mind. But it's kind of a long chance," says Moody, a 50-year-old homemaker.

Her mother and her sister-in-law had cancer. In part, Moody signed up to alleviate that feeling of helplessness that came from seeing their illnesses.

"You always feel like there's nothing you can do," she says quietly. Being a potential donor gave her "the feeling of being able to help someone. You might not have been able to help the person you wanted to, but there might be someone else you can help."

A regular blood donor (almost 7 gallons in her lifetime), Moody saw information on the bone marrow registry at the

By DONNA FREEDMAN
Daily News reporter

Donor happy to help save a life

Blood Bank. Then 49 years old, she slid in under the wire to sign up. (You can sign up until you're 50, and donate until you're 55.)

Just a few months later, in early August 1990, the call came: Moody might be a match for a young man from the Lower 48. She went back to the Blood Bank to give another blood sample and to get a lot of information on the procedure.

The closest place to donate marrow is the Fred Hutchinson Cancer Center in Seattle. That means a day's travel each way plus a 24-hour hospital stay. (All costs are paid by the recipient's insurance.)

Further testing of her

blood confirmed that she was a good match. Moody decided in mid-December to become a donor. She won't reveal exactly when she went to Seattle, saying that the hospital asked her not to be too specific, "for privacy reasons."

Once she signed the agreement, the patient in Seattle underwent massive doses of radiation and chemotherapy to destroy his own, diseased bone marrow. Moody was then "morally obligated" to go through with the transplant — with no bone marrow left, the man would die.

A donation can take place under general or spinal anesthesia. Moody chose a spinal. Doctors make between 100 and 200 needle punctures in the pelvic area, where there is plenty of bone — and marrow.

They withdraw a quart of marrow (three to five percent of the body's total). The

Please see Page C-2, DONOR

Eileen Albert had some blood work done last August, before a minor surgery. Routine stuff, except that the white-cell count looked high. Albert wasn't worried.

She felt fine. It was probably a hidden infection. But after no signs of infection were found, the doctor ordered a bone marrow biopsy.

Chronic myelogenous leukemia.

Albert's bone marrow was producing abnormal white blood cells. Eventually, the abnormal cells would crowd out any existing healthy blood cells. The only cure was a bone marrow transplant.

At first she was stunned and disbelieving. Then she was confident — "naive," she says now — that she would get the transplant and get on with her life.

About one-third of cancer patients find a donor within their families. Albert didn't.

By DONNA FREEDMAN
Daily News reporter

Cancer patient finds a cause

Then, and only then, did she face the reality of her illness.

"I felt sadness — maybe there wasn't a match for me (anywhere)," says Albert, a 37-year-old wife and mother of two sons. "Maybe I was going to ... not be around."

"The sadness is not being there for my kids. I still have things I want to teach them and experience with them."

Albert, a registered nurse now on leave from Fire Lake Elementary School, is a sturdy woman with pale skin and recently permed dark-blond hair. She looks healthy and fit, but that could change at any time.

On average, a chronic

myelogenous leukemia victim lives for 3½ years after diagnosis, but there are no guarantees. Albert could become seriously ill next week, or not for 10 years. Her chance of finding an unrelated donor are 1 in 26,000.

The numbers have given Albert a purpose. Since early February she's been speaking at local schools and service groups, and working with the Blood Bank of Alaska to get the word out about bone marrow donation.

At any given time, some 10,000 Americans need bone marrow transplants. The odds of finding a match range from one in 100 to one in a million, so it's not known how many potential donors would be needed to match all those people. Of the patients who find matches, only 20 percent actually get transplants. Poor physical condition or

Please see Page C-2, MARROW

Battered women: To kill or be killed?

By KAY BARTLETT
The Associated Press

NEW YORK — Richard Celeste, Ohio's outgoing governor, may have sparked a bigger chain reaction than any one foresaw when he granted clemency to 26 battered women serving time for killing their boyfriends or husbands.

He reviewed the cases of more than 100 women in December and decided there were 26 in self-defense.

a self-defense plea, a defense that has been around for over a decade, but one that some defense attorneys did not even know existed much less know how to use.

In late February, Maryland's Gov. William Schaefer commuted the cases of eight incarcerated women and commuted the sentences on the basis that they were in self-defense. Rep. Constance

Brown-bagging a lunch takes some forethought

By BILL TAMMEUS
Kansas City Star

From Washington, our

HUMOR

quite shocking to

MARROW: Cancer patient recruits donors

Continued from Page C-1

lack of money to pay for the \$150,000 procedure prevent the other 80 percent from going through with it. People without insurance must pay half the cost up front.

Nearly 230,000 Americans have signed up as potential donors with the National Marrow Donor Program, which matches donors with patients via computer.

A potential donor gives a small blood sample to be tested with the complex human leukocyte antigen system. Six key antigen types — genetic "markers" — are identified and coded. A family member's marrow must match five of six markers, but an unrelated donor's marrow has to match all six.

Albert's 2-year-old son,

They strongly believe they will find a marrow donor somewhere. Yet at the same time, they are aware of the odds.

Kyle, was a four-of-six match. Ironically, the woman's two brothers matched each other exactly. No one else in her family even came close to matching her.

Albert speaks about these things in a calm, matter-of-fact way. Her audiences — whether the Eagle River Llonesses or an elementary-school staff — react emotionally. They realize, perhaps for the first time, that this could happen to anyone. People cry when she talks.

They cry, and they act. In its first 18 months of existence, the local marrow registry had signed up 301 people. In just three weeks of public speaking, Albert brought in 104 more potential donors.

Others have donated money to the Eileen Albert Fund at the Blood Bank of Alaska. The human leukocyte antigen test costs \$56 per person, money the Blood Bank doesn't have right now. About \$9,100 has been raised to pay for tissue typing, and corporate sponsors like BP Exploration are paying for their employees' tests.

Albert is also responsible for legislation now before the Alaska Senate. When her husband, Steven, traveled to Juneau on business in late January, Albert sent along letters to her district's legislators. On March 6, Sen. Sam Colten, D-Eagle River, proposed a \$220,000 appropriation to the Blood Bank of Alaska. A concurrent resolution would designate April 14 to 20 Bone Marrow Donor Week.

Even if the money doesn't

come through, says Steven Albert, at least more people will be aware of the issue. "We've tried to focus attention on the population in general," he says, "as opposed to Eileen in particular."

They strongly believe they will find a marrow donor somewhere. Yet at the same time, they are aware of the odds.

"You have to be realistic, in the sense of recognizing what the probabilities are," Steven Albert says. "We have no expectations one way or another. If it happens, it happens. If it doesn't happen, then we make the best of that situation."

Says Eileen Albert: "We can't dwell on that. I would rather spend my time living than waiting to die."

That means savoring every day: the beauty of a suddenly blue late-winter sky; the coziness of an evening at home with their sons; the warm response of her friends who offer to do something, anything, to help.

"I don't know what the future holds. But I have faith it will work out. There's a point at which you have to act on faith and not out of fear," says Albert.

"I'm not ready to go. I'm not ready to check out yet. And I don't think I will."

DONOR: Says she'd give marrow again if needed

Continued from Page C-1

procedure lasts about 45 minutes, and after the anesthesia wears off the donor is free to resume normal activity.

The marrow replenishes itself in about two weeks. Moody says her physical recovery was much swifter.

"I felt a real dull ache in my lower back area," she says. "You limp a little bit, but that seems very minimal to me."

She took one Tylenol for discomfort, and was discharged in 24 hours. That same day she flew back to Anchorage.

Moody has never met the patient who received her marrow. He sent her candy and a card of thanks on Valentine's Day. The hospital handles communication between the two, unless they agree they would like to speak directly.

Moody feels that isn't necessary, yet.

"Right now I'm just satisfied in my own mind that I gave the marrow. I feel like I've done what I could at this point," she says.

She has another five years of donor eligibility left. It's unlikely she'd be called to donate again. But Moody isn't ruling it out.

"I would give marrow

again if I could," she says. "It takes such a little gift from the donor ... It's not really all that much. But oh, it's so necessary."

Alaskans can sign up at the Blood Bank of Alaska, 4000 Laurel St., between 8 a.m. and noon Mondays, or at the Eagle River office of the American Cancer Society, 11991 Business Blvd., Suite 103, between 4 and 6 p.m. Mondays.

Dale Goodloe, director of the Blood Bank, is particularly interested in minority donors. About 94 percent of American donors are of white, European ancestry. Minorities are vastly underrepresented, especially Alaska Natives.

"If an Alaska Native needs a transplant, the chances of finding a donor are about one in a million," says Goodloe.

He hopes to enlist new donors in Sitka, Juneau, Kenai and Fairbanks this year. However, that will probably happen only if service clubs and other groups from those communities will help defray costs.

"We need money and donors," Goodloe says. "The donors are much more important than the money, but unfortunately you need money to do the (tissue) typing."

DATEBOOK

In brief

• The Anchorage Board of Realtors will hold its general membership meeting for the month of March at 11:30 a.m. Wednesday at the International Airport Inn. Bill Allen will discuss "Building Together for Alaska's Future." Cost is \$11 for lunch, \$3 for coffee only. Information: 591-2339.

• A Parkinson's disease group will meet at 7 p.m. Wednesday at the Anchorage Senior Center. The group will discuss the benefits of physical and mental exercise. Information: Marie Alutius at 258-7823.

• The Anchorage Newcomers Club will convene at 10 a.m. Wednesday at the Clarion Hotel. Longtime Alaskan Estella Odstater will be the guest speaker. Information: Jo Jensen at 345-0227.

• The Alaska Pro Bono Program will sponsor a Pro Se Divorce Clinic from 10:30 a.m. to 1:30 p.m. Wednesday at the Fairview Community Center. The clinic is designed to instruct people in the filing of an uncontested default divorce. Information: 272-9431.

• The Anchorage Senior Center will provide free blood pressure screenings from 11 a.m. to noon Thursday at the Spenard Recreation Center. Information: Marie Alutius at 258-7823.

• MicroAge will host a benefit lunch for Bean's Cafe from 11:30 a.m. to 1:30 p.m. Thursday at 319 West Tudor Road. The menu includes a variety of bean soup:

TESTIMONY BEFORE THE SENATE FINANCE COMMITTEE

Prepared by: Dale V. Goodloe, Operations Manager
Blood Bank Of Alaska, Inc.

- An estimated 16,000 children and adults are stricken each year with leukemia, aplastic anemia, or other blood related diseases that can be successfully treated with bone marrow transplants.
- More than two thirds of these people cannot find a suitable marrow donor match within their own family.
- The National Marrow Donor Program was established in 1987, to assist patients in locating a suitable unrelated marrow donor with an identical tissue type.
- Finding a suitable marrow donor can be as high as one in a million based on the rarity of the tissue type and the availability of donors with the same racial background as the patient.
- Currently the National Marrow Donor Program registry is made up of 91% Caucasian.
- The Blood Bank of Alaska, established in 1962, is a not-for-profit blood center serving the blood needs of Alaskans. In July, 1989 the Blood Bank of Alaska became a recruitment center for National Marrow Donor Program. Currently, we are the only blood center and recruitment center in the State of Alaska.
- The Blood Bank of Alaska has become aware of people throughout Alaska in need of marrow transplants.
- As we became aware of Alaskans in need of marrow transplants, we have stepped up our efforts to enroll as many donors as possible into the National Marrow Donor Program; without a marrow transplant these people cannot survive.
- We have been working with volunteers and family fundraising efforts to recruit, test and enroll donors into the National Marrow Donor Program.
- With the interest and support expressed by individuals and communities throughout Alaska, we have come to realize the potential of recruiting thousands of Alaskans into the National Marrow Donor Program.
- Alaskans have already stepped forward to enroll as donors but we can only enroll as many as we have funds for.
- The Blood Bank of Alaska is a self-supporting blood center generating operating revenue from the recovery of expenses by means of a processing fee.
- The Blood Bank of Alaska does not receive funding from the Municipality of Anchorage, the State of Alaska, or from the Federal Government.
- The enrollment of Alaskans into the National Registry and supplying blood and blood components to patients throughout Alaska are two separate and distinct functions.

- The State of Alaska's support of funding is critical in not only the overall success of the National Marrow Donor Program, but to the people of Alaska in dire need of marrow transplants.
- The Blood Bank of Alaska is asking, on behalf of the many Alaskan's throughout the State and the thousands of patients throughout the United States, that the State of Alaska consider a one time appropriation of \$222,000 to be used for the direct cost of recruiting 3000 additional donors into the National Marrow Donor Program.
- As a combined effort of advanced medical and scientific research, volunteer donors, the State of Alaska, and the Blood Bank of Alaska, we can offer hope and life to thousands of people suffering from fatal, but now curable, leukemias and other blood related diseases.
- The Blood Bank of Alaska, Inc. respectfully urges the Senate Finance Committee's support for Senate Bill 177

Respectfully submitted,

BLOOD BANK OF ALASKA, INC.


Dale V. Goodloe
Operations Manager

PLEASE MICROFILM TOP PAGE ONLY.

**DOCUMENTS WHICH HAVE NOT BEEN FILMED BUT ARE
AVAILABLE IN THE ORIGINAL FILE INCLUDE:**

**CORRESPONDENCE AND STATEMENTS OF SUPPORT FOR SB 177
FROM:**

- 1. VALLEY HOSPITAL, PALMER, 4/2/91**
- 2. BLOOD BANK OF ALASKA, INC., ANCHORAGE,
4/2/91**
- 3. PHIL SMITH, JUNEAU, 3/25/91**
- 4. EILEEN L. ALBERT, EAGLE RIVER, ALASKA
3/12/91**