

SB 177

(11)

HOUSE COMMITTEE REPORT

Date Referred: April 29, 1991

FURTHER REFERRALS:

Date of Committee Action: _____

The FINANCE Committee considered:

SB 177

SENATE BILL NO. 177

APPROP: BLOOD BANK OF ALASKA, INC.

"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."

RECOMMENDATIONS:

the same title

be replaced with _____ a new title

have attached amendments(s)

do pass

do not pass

no recommendations

individual recommendations

additional referral to the _____ Committee

ADOPTS: _____ letter of Intent

ATTACHES NEW FISCAL NOTE(S): (Dept) _____

APPROVES PREVIOUS: (Dept/Date) _____

fiscal impact _____

fiscal note(s) _____

zero fiscal note _____

zero fiscal note(s) _____

SIGNING <u>DO</u> PASS	DP	OTHER RECOMMENDATIONS	DNP	NR	AM
<i>Mike Yavane</i> NAVARRE	✓	<i>Bob Mans</i> Sharp		✓	
<i>Mark Boyer</i> BOYER	X	<i>Richard</i> Hanson		X	
<i>W. Koponen</i> Koponen	✓				
<i>Terence Barnes</i> Barnes	X				
<i>W. Phillips</i> Phillips	✓				
<i>A. Ulmer</i> Ulmer	X				
<i>Ray Brown</i> Brown	✓				
<i>E.P. Mache</i> Mache					

Mike Yavane NAVARRE
E.P. Mache Mache
 CHAIRMAN'S SIGNATURE

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




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SENATOR SAM COTTEN

TO: Rep. Eileen MacLean, Co-Chair House Finance
Rep. Mike Navarre, Co-Chair House Finance

FROM: Sam Cotten 

DATE: May 3, 1991

RE: SB 177 "Appropriation to the Blood Bank of Alaska for
bone marrow donor program."

Thank you for bringing SB 177 before the House Committee on Finance for consideration.

I appreciate the fact that today the members of committee will have an opportunity to help address a critical public policy issue, which for a number of Alaskans is, simply put, a matter of life and death.

As the literature and other backup material indicates, medical advances have allowed for the successful treatment of leukemia and other blood related diseases. The problem is that there are far too few donors enrolled on the National Bone Marrow Donor Registry for most people afflicted with these fatal diseases to beat the statistical odds of finding the necessary perfect match.

The legislature can be of assistance by passing this one time appropriation to "jump start" recruitment of donors. The appropriation would fund type testing for 3,000 Alaskans. Included in this is a special outreach for a special outreach for up to six remote sites to ensure that the woefully under represented minority population, especially Alaska Natives, is increased.

This is not meant to replace, but rather to augment, the significant private efforts that have made to increase the number of available marrow donors. While volunteer efforts, especially in my community, have exceeded all expectations they just cannot generate the immediate increase in the donor pool that this appropriation would provide.

Passage of SB 177 will allow us to take a meaningful step in providing real hope for the hundreds of Alaskans, and thousands of Americans who will otherwise die for lack of a suitable marrow donor.



**BLOOD BANK OF ALASKA
AND
PUGET SOUND BLOOD CENTER BONE MARROW DONOR PROGRAM**

Previously, patients in need of a bone marrow transplant could be helped only if there was a tissue-matched donor within the family. Now, those without a matched related donor can be treated for such diseases as leukemia and aplastic anemia by receiving bone marrow from a healthy, unrelated donor.

However, in order to locate suitable unrelated donors for patients who need marrow transplants, there must be a pool of HLA-typed volunteers (HLA stands for human leukocyte antigen). The decision to become one of these volunteers requires serious consideration. This information package is designed to provide you with answers to commonly-asked questions about the marrow donation process and the transplant procedure. We hope this information will enable you to make a knowledgeable decision about joining a volunteer bone marrow donor registry.

BONE MARROW DONOR INFORMATION

Who qualifies as a bone marrow donor?

Unrelated volunteer donors must be between 21 and 55 years of age and must pass a comprehensive physical exam. Furthermore, their HLA type (tissue type) must match that of a patient who needs a bone marrow transplant.

What is an HLA type and how is it used?

The HLA type classifies people according to marker antigens on the surface of their white blood cells. The marrow of the donor whose HLA type matches that of the patient is much more likely to "take" than one that does not match.

What are the odds that an unrelated donor's HLA type will match that of a potential transplant candidate?

The odds are between 1 in 10,000 and 1 in 100,000 that any two unrelated individuals will have matching HLA types. Thus, it is critical to maintain a donor file with as many members as possible to increase the chances of finding a matched donor for every patient.

How are donors located?

Although physicians prefer family members because they offer the greatest chance of a successful transplant, only about 40 percent of those who need a transplant have a compatible related donor. For the 60 percent who don't, we must recruit donors from the general population. Nationwide, a central registry of over 200,000 people has been started to meet the country's requirement for unrelated bone marrow donors. A worldwide goal of one million donors has been targeted.

What laboratory tests are used to match donor and patient?

Everyone who agrees to enter the registry has a blood sample drawn to determine a preliminary HLA type. Later on, if this preliminary typing indicates that a donor may match a transplant candidate, another blood sample will be drawn for additional testing to confirm a perfect match.

How do matched donors learn more about what's involved in donating bone marrow?

Once the laboratory tests have confirmed that the donor is matched with a patient, the volunteer must decide whether to make the commitment to donate. Arrangements will be made for him or her to meet with a Blood Bank of Alaska or Puget Sound Blood Center physician to discuss the donation process.

After discussing the donation procedure, the potential donor is asked if he or she will sign the hospital consent forms authorizing the donation of bone marrow. At this point, the individual makes the final decision about donating before the patient is started on pre-transplant conditioning therapy. This is the point of "no return." The severity of the treatment means that the patient will die without a bone marrow transplant. Two weeks before the scheduled transplant date, the patient begins chemotherapy and radiation treatments designed to kill the diseased marrow. These treatments also allow the donated marrow to implant in the patient's marrow cavities and grow.

Can a matched donor say no?

Deciding to participate in a bone marrow transplant is a serious matter for all concerned. There may be many reasons for a potential donor who is perfectly matched with a transplant candidate to say "no." These reasons include such considerations as poor health, time involved, or concern about the risks. Even for related-donor transplants, family members sometimes decide against giving their marrow. Furthermore, whether potential donors agree to participate or not, their

identities remain confidential. Although the potential donor has a legal right to withdraw at any point in the selection process, once the patient's pre-transplant chemotherapy and radiation treatments have been started, there exists a moral obligation to follow through with the marrow donation. The doses of drugs and irradiation are lethal to the patient without the marrow rescue.

How is a donor's health evaluated?

Once consent for the marrow donation is given, donors undergo a complete physical examination by a physician who is knowledgeable about marrow donation but who is not employed by the Blood Center or by the Transplant Unit. The physician represents the donor and determines that the donor's health will permit a safe transplant for both donor and recipient.

Is the donor required to follow any special procedures before giving marrow?

There is no need to make any changes in diet, work, or social habits before the bone marrow donation, although we usually recommend that iron tablets be taken for a few weeks before donation to expedite replacing the blood present in the marrow. Iron tablets can cause stomach irritation which resolves if the medicine is stopped. Also, during the week before the procedure a donor should not take any unnecessary risks such as riding motorcycles, flying a small aircraft, etc. since his health is vital for the patient.

What's the first step in becoming a volunteer marrow donor?

The first step is to agree to participate in a marrow transplant registry by completing the Bone Marrow Donor Data form enclosed. When we receive your completed form, we will contact you to set up an appointment to come in to the Blood Bank of Alaska. Also, we will need to draw a blood sample for HLA typing.

If I register as a volunteer marrow donor, what are my chances of actually being used as a donor?

There are common and uncommon HLA types. If yours is a common type, the chances that you will match a transplant candidate are much greater than if your type is rare. It's possible that you will never be called. But if you are, you will always have the option of deciding not to donate.

If I'm found to be a matched donor and agree to proceed, who covers my expenses?

Expenses incurred for medical examinations and hospital stay are paid by the transplant patient's medical insurance. Travel expenses and other non-medical costs are also the patient's responsibility. Life and disability insurance policies covering the procedure are provided by the patient to the donor at no charge. The patient shall be responsible for any required followup care of the donor if complications occur. Compensation for loss of work is handled, if necessary, on a case-by-case basis with the donor's employer.

What's involved in removing the donor's marrow?

Bone marrow for transplantation is removed from the hip bones during an aspiration procedure. All donors receive some form of anesthesia--either a general anesthetic, which puts you to sleep during the procedure, or a spinal anesthesia to deaden feeling in the area of the body where the punctures are made in each hip. Twenty to thirty extractions of marrow are made through each of these punctures to draw the marrow out of the bones. Typically, the donation procedure lasts from 45 to 90 minutes.

Between 3 to 5 percent of the total bone marrow is removed, an amount not large enough to cause anemia. The donor will also usually receive a pint of their own blood taken and stored one to three weeks before the donor's marrow donation. Within several weeks, the marrow will be replaced by normal processes. Except for some soreness in the hips that may last for a few days, donors generally experience no other problems.

Where will the donation take place?

Because a highly trained physician specializing in marrow aspiration must perform the aspiration, donors from Alaska will be flown to Seattle, where the aspiration will take place. All costs associated with the travel and hospitalization of the donor will be covered by the patient's insurance.

When and for how long is the donor hospitalized?

Typically, the marrow donor enters the hospital the day of the donation. Because of the effects of the anesthesia, and because the donor's hips may be painful from the aspiration of marrow, donors usually remain in the hospital for one to two days.

After the donation, how long does it take to get back to normal?

The time required for a complete recovery varies but most donors resume their usual activities in a few days. Others may take up to a week but rarely longer.

Once people have donated, can they donate again?

Because the body replaces the donated bone marrow, it is medically possible to donate more than once. Although it is unlikely that someone would be called again, it's possible that a former marrow donor will later be found to match another patient. However, it is unlikely that we will ask a donor to give more than once to the same patient.

What are the risks for the donor?

It is possible to have a bad reaction to anesthesia, including sudden fall in blood pressure, abnormal heart beats and very rarely, death. However, to date, over 2000 bone marrow transplants have been performed in Seattle without a donor fatality. There have been rare instances of temporary complications such as fevers or greater than expected bleeding from aspiration sites.

INFORMATION ABOUT MARROW TRANSPLANTATION

Who needs bone marrow transplants?

Bone marrow transplants are used to treat patients with aplastic anemia (a disease in which the body stops producing blood cells) and some types of leukemia (a cancer of the blood). In both of these diseases, replacing the bone marrow with new, healthy marrow has markedly increased the chances of curing the patient's disease.

How is the patient prepared for the transplant?

For the patient, preparation begins well in advance of the transplant. The patient's diseased bone marrow is destroyed through the use of a combination of radiation and chemotherapy treatments.

At this point, there is no turning back for the patient. The marrow-destroying treatments are fatal in themselves, unless healthy marrow is immediately transplanted.

How do patients receive the marrow?

Patients receive the marrow much as if it were a blood transfusion. The marrow, a liquid resembling whole blood, is transfused intravenously into the patient's bloodstream. The transplanted marrow naturally grafts itself within the patient's bones, replacing the previously diseased marrow. During the transplant procedure the patient experiences virtually no pain.

What are the first signs that the transplant is a success?

Once the donated marrow enters the patient's bloodstream through transfusion, it takes about two weeks to see the first evidence of a graft, indicating that the new marrow has started to grow in the patient. A noticeable rise in the patient's white blood cell count is the first sign that the graft has occurred. The white blood cell count will continue to increase, and eventually there will be evidence of marrow production of platelets and red cells as well as white cells.

What complications does the patient experience?

In addition to side effects caused by chemotherapy and radiation treatments used to prepare the patient for transplant (nausea, vomiting, hair loss, diarrhea, and appetite suppression), there are several complications that may result from the transplant itself. These include rejection (no graft occurs); graft-versus-host disease (the new marrow tries to reject the patient's body and causes infection and inflammation); infection (the result of destroying the patient's entire immune system in preparation for transplantation); and relapse (the original disease reappears in the bone marrow).

Can such complications be treated successfully?

Most of these complications have been treated successfully. Response to treatment is directly related to the severity of the problem. In the most severe cases the patient's chances for survival are poor.

May the donor meet the patient who receives his or her bone marrow?

If both parties are agreeable, donors may meet their bone marrow recipient at such time after transplant that engraftment is ensured and there are no medical problems. However, donors are told about the recipient's condition at the time they agree to donate and may, with the patient's consent, continue to receive progress reports during the patient's hospital stay and beyond, if they wish.



BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE ALASKA 99508

(907) 563-3110

**BLOOD BANK OF ALASKA IN CONJUNCTION WITH
PUGET SOUND BLOOD CENTER
UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE**

CONSENT TO JOIN A VOLUNTEER MARROW DONOR REGISTRY

Patrick G. Beatty, M.D., Associate Professor of Medicine
(206) 292-1897

Franc A. Fallico, M.D., Blood Bank of Alaska Medical Director
(907) 563-3110

INVESTIGATORS' STATEMENT

Purpose and Benefits

Leukemia and aplastic anemia are fatal diseases of the blood which can be treated with chemotherapy, immunotherapy, and/or irradiation. In some instances, bone marrow transplantation is the treatment of choice. Marrow transplantation permits the use of much greater doses of chemotherapy or irradiation in leukemic patients to destroy as many malignant cells as possible. Since these doses also destroy the patient's ability to make new cells, normal marrow must be provided from a healthy donor to rescue the patient. Most patients who might benefit from such treatment do not have a matched sibling available as a donor. We are recruiting a large number of volunteer unrelated bone marrow donors into a registry that would only be accessible to authorized personnel for matching potential donors with transplant candidates. There is no direct benefit to you as a result of joining the Bone Marrow Donor Registry.

Procedures

To be considered for the registry, a potential marrow donor must be between the ages of 21 and 55 and in good health. Entry in the registry does not commit a potential donor to donation. It only gives registry personnel permission to contact a potential donor for further discussion and additional blood tests if a closely matched patient is identified. Even at that time, the potential donor's name will not be released to the patient, the patient's family, or the patient's physician without the written permission of the donor. Although the potential donor has a legal right to withdraw at any point in the selection process, once the patient's pre-transplant chemotherapy and radiation treatments have been started, there exists a moral obligation to follow through with the marrow donation. The doses of drugs and irradiation are lethal to the patient without marrow rescue.

Volunteers for the bone marrow donor registry will be asked for their name, address, telephone number, birth date and, at their option, social security number (social security numbers will be used only for identification purposes). If blood has not already been drawn in the course of a routine blood donation, 4 teaspoons of blood will be drawn for tissue typing. Volunteers will be contacted approximately every two years to confirm continuing interest and update the address list. Registry data shall be kept locally. It is possible that a marrow donation may be shipped to recipients elsewhere in the United States.

Risks, Stress or Discomfort

At such time as you may be found to be a suitable match for a specific patient, the risks of the bone marrow aspiration procedure will be discussed in detail. In brief, these include the risks of general or local anesthesia and the anticipated pain, soreness and bruising from the needle punctures through the skin into the hip. The insertion of a needle to draw blood may cause temporary discomfort and a bruise may form at the site where the needle enters the vein. Details may be found in the accompanying information package. An additional consent form describing the aspiration procedure will be provided for signature at that time.

Other Information

There will be no costs to you for HLA typing or for entering your name in the marrow registry. Any expenses would be covered by the patient receiving the marrow. You are free to refuse to participate and to withdraw from the study at any time without penalty or loss of benefits to which you are otherwise entitled. Your identity will be kept confidential with only authorized local registry personnel having access to your identifying data. Your registry data will be maintained on file until you reach age 55.

INVESTIGATOR'S SIGNATURE _____

DATE _____

SUBJECT'S STATEMENT

You may perform HLA typing on a research blood sample drawn from me. I agree to allow my name, HLA typing information, and results of any virology testing to be placed into a local registry at the Blood Bank of Alaska and also at Puget Sound Blood Center. I understand that my HLA type, but not my name, will also be entered into a national registry. I will not be charged for having my blood HLA typed or for having my HLA type entered into the registries. I may be contacted by the local registry personnel about further blood drawing and tissue typing if a patient who may benefit from my bone marrow is identified. This registry consent does not place me under any obligation to proceed with the donation process. I voluntarily consent to participate in this study. I acknowledge receipt of a signed copy of this consent form. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about subject's rights will be answered by a Blood Bank of Alaska representative.

SUBJECT'S SIGNATURE (For informational purposes only; keep this for your records.) _____

DATE _____

cc: Subject



BLOOD BANK OF ALASKA, INC.

4000 LAUREL STREET • ANCHORAGE, ALASKA 99508

(907) 563-3110

BONE MARROW DONOR DATA FORM

PLEASE RETURN TO THE BLOOD BANK OF ALASKA, INC.

Date: _____

Please provide the following information as you wish it to appear in your Bone Marrow Donor Program permanent file. Notify the Blood Bank of Alaska, Inc. of any name, address, or telephone changes. [This information does not appear in the Bone Marrow National Registry. Only your HLA typing data and an identifying code will appear in the Registry.]

Name (print): _____

Permanent Address: _____

City: _____ State: _____ Zip: _____

Social Security No.: _____ Date of Birth: _____

Home Phone: (____) _____ Work Phone: (____) _____

Person(s) to contact if we cannot reach you at the above address or phone number(s) Please list as many names as possible.

Name: _____ Phone: (____) _____

Name: _____ Phone: (____) _____

Name: _____ Phone: (____) _____

Name: _____ Phone: (____) _____

Have you ever donated blood at the Blood Bank of Alaska? Yes ___ No ___

Approximate date of last donation ____/____/____
Month Year

Optional Information: Certain HLA types are more common in various ethnic groups. Indicate which ethnic group you are a member of in order to assist in matching donors with patients.

- | | | | |
|----------|---------------|----------|-------------------|
| 1. _____ | Caucasian | 5. _____ | Native American |
| 2. _____ | Black | 6. _____ | Hispanic |
| 3. _____ | Oriental | 7. _____ | Other |
| 4. _____ | Alaska Native | 8. _____ | Decline to Answer |

B.B.A. USE ONLY:
Date and time HLA Specimen drawn: _____

AIDS INFORMATION SHEET

WHAT IS AIDS? AIDS (Acquired Immune Deficiency Syndrome) is a condition in which the body's normal defense mechanisms against certain diseases or conditions are reduced. As a result, patients often develop unusual infections, such as Pneumocystic pneumonia or a rare form of skin cancer, Kaposi's Sarcoma.

WHO IS AT RISK? If you are an individual in any of the following categories, or if you are the sexual partner of an individual in any of the following categories, you are at high risk of contracting the disease:

- o Those who have one of its signs and symptoms such as: unexplained weight loss; night sweats; blue or purple spots typical of Kaposi's sarcoma on or under the skin, or spots or unusual blemishes in the mouth; fever over 99 degrees for more than 10 days; persistent cough and shortness of breath; swollen lymph nodes lasting more than one month; persistent diarrhea; or individuals who have had positive anti-HIV test results.
- o Past or present abusers of intravenous drugs.
- o Males who have had sex with another man, even one time since 1977.
- o Persons born in or emigrating from countries where heterosexual activity is thought to play a major role in transmission of HIV-2 infection (e.g., sub-Saharan Africa, and islands located near these areas of Africa).
- o Individuals with Hemophilia or related clotting disorders who have received clotting factor concentrates.
- o Men and women who have engaged in sex for money or drugs since 1977, and persons who have been their heterosexual partners within 12 months.
- o Persons who have had, or been treated for, syphilis or gonorrhea (Clap, the Drip, Strain, Louies, Bad Blood) during the preceding 12 months.
- o Persons who have received a transfusion of whole blood or a blood component within the past 12 months.

The Blood Bank of Alaska is not a diagnostic service. There is an interval during early infection when the HIV antibody test may be negative although the infection may still be transmitted. If you are interested in your HIV antibody status, the Public Health Service located at 825 L Street provides testing and counseling for a nominal charge which may be waived if necessary. Call 343-4611 for additional information.

BONE MARROW DONOR HEALTH HISTORY

NAME: _____ DATE: _____

SOC. SEC. No. _____ DATE OF BIRTH: _____

- 1. Y() N() Are you between the ages of 21 and 55?
- 2. Y() N() Are you in good general health?
- 3. Y() N() Have you read and do you understand the "AIDS Information Sheet" and the "Bone Marrow Donor Information" handout?

NOTE: "YES" answers to the questions below do not automatically disqualify you. Please explain any "yes" answers in detail in the space provided below so your response can be properly evaluated.

- 4. Y() N() Have you ever been refused as a blood donor or had problems donating blood?
- 5. Y() N() Have you ever had cancer, diabetes, blood disease, or other chronic illnesses?
- 6. Y() N() Have you ever had chest pain, shortness of breath, heart attack, or other heart disease?
- 7. Y() N() Have you ever had hepatitis, yellow jaundice, liver disease, or a positive test for hepatitis?
- 8. Y() N() Have you ever had a positive test for AIDS antibodies? Have you ever been exposed to anyone with AIDS or with a positive test for AIDS antibodies? (Please refer to the AIDS Information Sheet.)
- 9. Y() N() Have you received any blood transfusions or tattoos during the past 12 months?
- 10. Y() N() Have you ever had malaria, or taken preventative medicine for malaria?
- 11. Y() N() In the past month have you taken any prescription drugs? (list below)
- 12. Y() N() Have you ever taken pituitary growth hormone or the medications Accutane or Tegison?
- 13. Y() N() Have you ever taken drugs by needle not prescribed by a physician, or have you ever had sex with someone who has?
- 14. Y() N() Have you taken clotting factor concentrates for a bleeding disorder such as hemophilia, or have you had sex with someone who has?
- 15. Y() N() Have you had, or been treated for, syphilis or gonorrhea in the past 12 months?
- 16. Y() N() Have you taken money or drugs in exchange for sex any time since 1977?
- 17. Y() N() Have you given money or drugs to someone to have sex with you at any time in the past 12 months?
- 18. Y() N() MALES: Have you had sex with another man since 1977 (even one time)?
Y() N() FEMALES: Have you had sex with a man who has had sex with another man (even one time) since 1977?
- 19. Y() N() Were you born in or have you moved to the U.S. from Sub-Saharan Africa or the islands close to that part of Africa, or have you had sex with someone who has?

EXPLANATION(S) TO "YES" ANSWERS (except No. 1,2,&3): _____

SIGNATURE _____ FULL NAME _____

(please print)



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(907) 563-3110

CONSENT TO JOIN A VOLUNTEER MARROW DONOR REGISTRY

SUBJECT'S STATEMENT

You may perform HLA typing on a research blood sample drawn from me. I agree to allow my name, HLA typing information, and results of any virology testing to be placed into a local registry at the Blood Bank of Alaska and also at Puget Sound Blood Center. I understand that my HLA type, but not my name, will also be entered into a national registry. I will not be charged for having my blood HLA typed or for having my HLA type entered into the registries. I may be contacted by the local registry personnel about further blood drawing and tissue typing if a patient who may benefit from my bone marrow is identified. This registry consent does not place me under any obligation to proceed with the donation process. I voluntarily consent to participate in this study. I acknowledge receipt of a signed copy of this consent form. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about subject's rights will be answered by a Blood Bank of Alaska representative.

SUBJECT'S SIGNATURE: _____

DATE: _____

cc: Subject



BLOOD BANK OF ALASKA, INC.

4000 LAUREL STREET • ANCHORAGE, ALASKA 99508

(907) 563-3110

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.
- o 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.

BUDGET OVERVIEW

1. PERSONNEL

3 Part-Time Employees \$ 33,775

2. TRAVEL

Mileage @ 26 Cents/Miles 825

3. EQUIPMENT

One-Time Equipment 1,375

4. SUPPLIES & HLA TYPING

HLA Typing (@ UCLA) 130,000

Supplies 11,950

5. OTHER EXPENSES

Shipping, Telephone, Printing 7,570

SUBTOTAL \$ 185,500

The following additional funding is needed
to recruit 450 bone marrow donors from small
communities throughout the state.

-	Personnel	\$ 6,050
-	Air Fare	4,500
-	HLA Typing & Supplies	24,950
-	Shipping/Telephone	800

Additional Expense for Remote Locations SUBTOTAL \$ 36,300

TOTAL EXPENSES: \$ 221,800

ANNUAL

3. EQUIPMENT

(One Time Purchase)

Fireproof Locking File Cabinet	\$	800
4 Each Blood Pressure Cuffs		300
Off-Site Phlebotomy Carrying Cases		275

TOTAL EQUIPMENT	\$	1,375
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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
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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
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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
---	--	-------

TOTAL SUPPLIES	\$	141,950
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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	525
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

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/>
	ADDT'L PERSONNEL EXPENSE	\$ 6,050

TRAVEL

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

ADDT'L TRAVEL EXPENSE \$ 4,000

SUPPLIES

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

ADDT'L SUPPLIES EXPENSE 24,950

TELEPHONE/FAX

ADDT'L TELEPHONE/FAX EXPENSE 500

SHIPPING SPECIMENS TO BBA

ADDT'L SHIPPING EXPENSES 300

TOTAL ADDITIONAL EXPENSES \$ 36,300



BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE, ALASKA 99508

(907) 563-3110

May 7, 1991

House Finance Committee
Representative Eileen MacLean, Co-Chair
Representative Mike Navarre, Co-Chair
P.O. Box V
Juneau, AK 99811

TESTIMONY BEFORE THE HOUSE FINANCE COMMITTEE

Prepared By: Dale V. Goodloe
Operations Manager, Blood Bank of Alaska

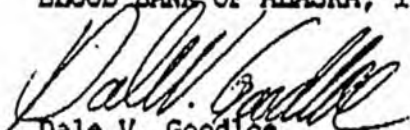
- o An estimated 16,000 children and adults are stricken each year with leukemia, aplastic anemia, or other blood-related diseases that can be successfully treated with bone marrow transplants.
- o More than two-thirds of these people cannot find a suitable marrow donor match within their own family.
- o The National Marrow Donor Program was established in 1987 to assist patients in locating a suitable unrelated marrow donor with an identical tissue type.
- o 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.
- o Currently, the National Marrow Donor Program Registry is made up of 91% Caucasian donors.
- o 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 the National Marrow Donor Program. Currently, we are the only blood and recruitment center in the State of Alaska.
- o The Blood Bank of Alaska has become aware of people throughout Alaska in need of marrow transplants.
- o 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.
- o We have been working with volunteers and family fundraising efforts to recruit, test, and enroll donors in the National Marrow Donor Program.

House Finance Committee
May 7, 1991
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- o 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.
- o Alaskans have already stepped forward to enroll as donors, but we can only enroll as many as we have funds for.
- o 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.
- o The Blood Bank of Alaska does not receive funding from the Municipality of Anchorage, the State of Alaska, or from the Federal Government.
- o The enrollment of Alaskans into the National Registry and supplying blood/blood components to patients throughout Alaska are two separate and distinct functions.
- o 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.
- o 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 3,000 additional donors into the National Marrow Donor Program.
- o 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.
- o The Blood Bank of Alaska, Inc., respectfully urges the House Finance Committee's support for Senate Bill SB177.

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. THE TSONGAS COMMITTEE, 5/7/91**
- 2. ALASKA NURSES· ASSOCIATION, RESOLUTION 6.
5/6/91**
- 3. EILEEN L. ALBERT, EAGLE RIVER, ALASKA
5/3/91**