

HB

211

March 12, 1991

Representative Betty Bruckman
House of Representatives
P.O. Box V Capitol, Room 116
Juneau, Alaska 99811

Dear Representative Bruckman:

Thank you for your interest in sponsoring Bone Marrow Donor Program legislation. For your reference, I have enclosed information about our efforts to recruit Alaskans as bone marrow donors.

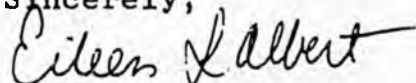
As you know, I have leukemia and am searching for a compatible donor who may save my life through a bone marrow transplant. During my search, I have discovered that 9000-10,000 other individuals throughout Alaska and the United States share this need to find a compatible marrow donor. I have also found that as the public becomes aware of this urgent need, many of my fellow Alaskans are eager to step forward to become marrow donors, not just for myself, but for anyone who might need a bone marrow transplant. Many of these people have shared with me how their lives have also been touched by parents, children, siblings, friends, and co-workers with leukemia and other blood-related diseases that can be cured through bone marrow transplants.

What started as a local Eagle River community response to my personal need has become a rapidly-growing effort in Anchorage and the Matanuska-Susitna Valley to support the needs of other families in similar catastrophic situations. Through volunteer time, private donations, and collaboration with the Blood Bank of Alaska, my family and friends have enrolled over 300 potential donors into the National Marrow Donor Program in the past six weeks.

We are excited now about the prospect of legislation providing funding for the Blood Bank of Alaska to recruit an additional 3000 Alaskan marrow donors. This funding will enable the Blood Bank to increase its public education and blood-testing of potential bone marrow donors from communities throughout our state. This effort will also begin to meet the needs of ethnic minorities such as Alaska Natives, who currently have little hope of finding compatible donors due to their under-representation in the donor registry.

We look forward to working with you to assure successful passage of Bone Marrow Donor Program legislation.

Sincerely,



Eileen L. Albert
17708 Kiloana Circle
Eagle River, Alaska 99577
(907) 694-5781

correspondence

ALASKA STATE HOUSE



REPRESENTATIVE BETTY BRUCKMAN

MEMORANDUM

TO: Representative Georgianna Lincoln
Co-chair, House HESS Committee

FROM: Representative Betty Bruckman

DATE: March 14, 1991

SUBJECT: HCR 16 (Bone Marrow Donor Week)
HB 211 (Special Appropriation)

I have introduced HCR 16 and HB 211 in an effort to educate persons regarding bone marrow transplants and to provide funding for efforts to increase enrollment in the donor program.

HCR 16 designates the week of April 14-20 as "Bone Marrow Donor Week". The resolution asks that efforts be made, in conjunction with the work being done by the Blood Bank of Alaska, to educate and inform Alaskans about the bone marrow donor program.

HB 211 requests an appropriation of \$222,000 as a grant to the Blood Bank of Alaska to assist in increasing enrollment of marrow donors in Alaska, with particular attention to enrolling Alaskan Native donors who are severely under represented in the nationwide marrow registry.



March 20, 1991

House HESS Committee
Representative Pat Carney, Co-Chair
Representative Georgianna Lincoln, Co-Chair
P.O. Box V
Juneau, Alaska 99811

c/o Representative Betty Bruckman

TESTIMONY BEFORE THE HOUSE HESS 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 can not find a suitable marrow donor match with in 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, Inc. became a recruitment center for National Marrow Donor Program in July 1989 and remains the only recruitment center in the State.
- 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 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 State of Alaska's support of the resolution and 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, Inc. respectfully urges the House HESS Committee's support for House Bill 211 and House Concurrent Resolution 16.

Respectfully submitted,


Dale V. Goodloe

Blood Bank Testimony



March 21, 1991

The Honorable Ted Stevens
522 Hart Senate Office Building
Washington, D.C. 20510

VIA FACSIMILE

National Coordinating Center
1433 Broadway Street N.E.
Suite 400
Minneapolis, MN 55413
612 627-5800
1 800-526-7877
FAX 612 627-5899

Dear Senator Stevens:


As a follow-up to your conversation with Congressman Bill Young yesterday, I am forwarding the names of two Alaskans who have been so integral to the prairie fire of marrow donor recruitment which has been taking place in your state.

Julian Darley, who heads British Petroleum Exploration in Alaska has played a leadership role in the company's decision to sponsor employee recruitment. This step by British Petroleum America is highly significant because of the company's international status. As you know, I have been most active in helping to develop a worldwide marrow donor network. British Petroleum's corporate responsiveness will certainly benefit our U.S. Registry and the patients we serve but it can also serve as an inspiration to other companies here and abroad to do likewise. This step is a wonderful example of private sector support for a congressionally-authorized program. I hope you will share my enthusiasm for the company's effort.

Dale Goodloe, the operations manager at our satellite donor center in Alaska (907/563-3110), has made sure that your state's prairie fire is moving in the right direction. Over the Congressional recess, there may be a recruitment activity which you wish to participate in or observe. Mr. Goodloe is very well aware of your special role in assuring that the National Marrow Donor Program was created and has the resources to expand enough to serve as a national and international treasure.

I have asked Liz Quam from the NMDP staff to Federal Express a packet about the program to both your Capitol and district office but I wanted to respond immediately with the above names. I will personally keep you updated on plans for a joint press conference with James Ross, CEO of BP America. We would certainly welcome your participation if your schedule permits.

Best regards,


Admiral E. R. Zumwalt, Jr., USN (Ret.)

A collaborative effort of the

American Association of Blood Banks
Council of Community Blood Centers

cc: Congressman Bill Young
Julian Darley
Keith Owan
Dale Goodloe

With funding from
The National Heart, Lung,
and Blood Institute and
Naval Medical Research and
Development Command

A GIFT OF LIFE

My name is Eileen Albert. I am an RN currently on leave from my job as Fire Lake Elementary School nurse. I am 37 years old. My husband Steve is a wildlife biologist employed by the Department of Fish and Game. We have two sons, ages 8 and 2. Our family has lived in Eagle River for eight years.

In September 1990, I was diagnosed with **Chronic Myelogenous Leukemia (CML)**, a cancer of the blood-forming cells in my bone marrow. CML is a progressive disease that has an average survival time of 3 1/2 years.

The only known cure for CML is a **Bone Marrow Transplant**. After the patient's bone marrow has been destroyed by chemotherapy and radiation treatments, bone marrow cells from a healthy donor are transfused into the patient's veins through an IV, just like a blood transfusion. The cells replace the destroyed bone marrow, and within two to three weeks the transplanted bone marrow begins to produce normal blood cells in the patient.

To date, members of my immediate and extended family have been tested as potential donors, but the test results have been negative. Our search now widens to the general population, where the chance of finding a compatible donor is 1 in 20,000. I am asking for your help in this fight for my life.

You can help in several ways:

1) You, as individuals, can register as **volunteer bone marrow donors**. You must be between 21 and 55 years old, have no history of hepatitis, heart disease, cancer, or AIDS, be no more than 25% overweight, and sign a standard consent form allowing your name to be included in the National Marrow Donor Program. Through a simple blood test, your blood would be drawn and analyzed to identify your Human Leukocyte Antigen (HLA) type, or "tissue type" (This is different from your "blood type"). This information is placed into a computerized data bank called the National Registry. When a search of the registry identifies a match with a patient, you are contacted for additional tests and to make a final decision about becoming a marrow donor. A donor's marrow is collected during a hospital procedure, performed under anesthesia, using a needle and syringe to extract three to five percent of the donor's marrow from the pelvic bones. Within two to three weeks, the donor's body naturally replaces the donated marrow. The donor typically experiences discomfort and tenderness in the hips for a few days. Costs of the procedure are covered by the patient's insurance. If you are interested in becoming a donor, you may contact your **school nurse**, or **Dale Goodloe** at the **Blood Bank** at 563-3110 for more information.

2) Another way to help is to **contribute money for HLA tissue typing**. Each blood test costs \$56.00, and thousands of HLA typings are sometimes needed before a match can be found. Funds which are raised for the **Eileen Albert Fund** will be used to cover costs of tissue typing of volunteer bone marrow donors. Tax-deductible donations may be made to:

**Blood Bank of Alaska
Bone Marrow Donor Program
Attn: Eileen Albert Fund (please note this fund on your check)
4000 Laurel St.
Anchorage, AK 99508**

3) Your organization can sponsor either a **Donor Drive** and/or a **Fundraising Program** for tissue typing. I would like to attend any appropriate meetings of your group to share information about leukemia and bone marrow transplants. You may contact me through the Blood Bank at 563-3110.

Thank you for your concern and consideration of our needs. Your efforts will benefit not only me, but also thousands of others awaiting bone marrow transplants by increasing the number of possible donors available. I look forward to hearing from you.

Eileen Albert

 * DELIVER TO: LHSCHES *
 * ORIGINAL *
 * SENT: 03/26/91 TIME: 09:55 *
 * FROM: LIUCLAI *
 * SUBJECT: 91-03-128,FS,BLOOD ETC.,3-26 *
 * PRINT DATE: 03/26/91 TIME: 11:18 *

SUBJECT LINE TO READ. TC NO.; FLNFS;SHORT SUBJECT;DATE

TXC NO: 91-03-128
 DATE: 03-26-91
 SPONSOR: H MESS
 SUBJECT: HCR 16, SCR 17, HB 211, HB 43, HB 163
 MODERATOR: LANI
 SITE: ANCHORAGE

FINAL STATS

TO TESTIFY

NAME\ REPRESENTING	ADDRESS	PHONE	BILL NO.
1. ANNABELL STEVENS	2906 W 30TH	279-1124	HB 166
2. DALE GOODLOE	BLOOD BANK OF AK.	563-3110	SCR17, HB211

*Interim Pres.
 AK Caddo+Moms*

3. GARY MAXWELL	2225 ARCTIC BLVD.	274-7358	HB 43
4. ROLAND GOWER, MD	2841 DEBARR #41	279-3564	SCR 17, HB211

TO OBSERVE:

NAME\ REPRESENTING	ADDRESS	PHONE	BILL NO.
1. VICKIE MONINSKI	15720 SOUTHPARK LP.	346-1460	SCR17, HB211
2. TED MONINSKI	BOX 102776	346-1460	
3. GEOFF FEILER	4128 WRIGHT ST,	561-0083	SCR17, HB211
4. LINDA WEBBER, PH D	1227 W 9TH, #200	276-4910	

TESTIFIED: 3
 UNABLE: 1 (ROLAND GOWER, MD)
 OBSERVED: 4
 TOTAL: 8

STARTING TIME: 7:30 A.M. ENDING TIME: 10:00 A.M.

HOUSE COMMITTEE REPORT

(7)

Date Referred: March 13, 1991

FURTHER REFERRALS:

Finance

Date of Committee Action: 3-26-91

The HEALTH, EDUCATION AND SOCIAL SERVICES Committee considered:

HB 211

HOUSE BILL NO. 211

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:

be replaced with _____ the same title
 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>Ashley Davis</i>	✓				
<i>Mary Miller</i>	✓	<i>Mark Hanley</i> (HANLEY)			
<i>Bettie Davis</i>	✓				
<i>Joe Gonzales</i> (GONZALES)	✓				
<i>John Carney</i> (CARNEY)	✓				
<i>Lincoln</i> (LINCOLN)	✓				

[Signature]
CO-CHAIRMAN'S SIGNATURE



Alaska State Legislature
House of Representatives
 COMMITTEE ON HEALTH, EDUCATION
 AND SOCIAL SERVICES

SUBJECT OF MEETING:
 HB211 APPROPRIATION: BLOOD BANK OF
 ALASKA, INC.

DATE: March 26, 1991

PLACE: Capitol Room 106

NAME	REPRESENTING	BUSINESS/PERSONAL MAILING ADDRESS	ZIP	(H) PHONE	(W) PHONE	DO YOU WANT TO TESTIFY?		WHAT SUBJECT/ WHICH BILL?
Bill Stoffze	Sen. Cotten					Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	
						Y	N	



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

CONSENT TO JOIN A VOLUNTEER MARROW DONOR REGISTRY

Thomas Price, 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

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)

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.



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

Eileen Albert and her family thank you for your interest in the Bone Marrow Donor Registry.

To enroll in the registry, you must be between 21 and 55 years old and complete a donor health assessment. Please carefully review the attached information describing why bone marrow transplants are needed, how donors are selected, and the potential risks and complications of bone marrow donation.

If, after reviewing this information, you are sincerely interested in becoming a bone marrow donor, you will need to complete three "pink" forms:

Bone Marrow Donor Data Form
Bone Marrow Donor Health History
Consent to Join a Volunteer Marrow Registry.

Return these pink forms in a sealed envelope to your school nurse, to Dale Goodloe at the Blood Bank of Alaska, or to the American Cancer Society office, 11901 Business Blvd., Suite 103, Eagle River.

After your medical information has been reviewed, you will be contacted to come to the next scheduled marrow donor drive. Blood samples are drawn each Monday from 8:00 AM-12:00 Noon at the Blood Bank of Alaska and from 4:00-6:00 PM at the American Cancer Society office in Eagle River. A sample of your blood (one test tube) will be drawn during the donor drive and shipped by overnight courier to the UCLA laboratory for HLA typing.

Your HLA type, but not your name, is then included in the National Marrow Donor Registry. You will remain an active member of the registry until age 55 or until you notify us otherwise. Please let us know of address or phone changes.

Should you be identified as a possible match to a patient, you will be contacted directly, and additional confirming blood testing may follow. If the match is compatible, an educational meeting will be set up for you and your family at the Blood Bank of Alaska. A thorough physical examination in Seattle is the next step. If all results are good, and you wish to donate, an intent to donate is signed. We then work together to schedule an aspiration date at Virginia Mason Hospital in Seattle. All expenses are paid; please, however, give consideration to time away from home and work.

Your interest and support of the Bone Marrow Donor Registry is most appreciated. Please feel free to call Dale Goodloe at (907) 563-3110 if you have further questions.

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.

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	525
Printing (excluding information packages); handouts to potential donors concerning future draw sites, miscellaneous information for donors	300
Miscellaneous; donor acknowledgements, etc.	150

TOTAL OTHER \$ 7,570

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
------------------------	-----------------

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
---	--	-------

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/>
	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