SCR

17

STATE OF ALASKA
1990 LEGISLATURE

BILL VERSION CS SCR 7 (Hess)
PUBLISH DATE 10-Apr-91

FISCAL NOTE

REQUEST: SENATE HESS COMMITTEE
Revision Date:
Affected Agency: Legislative Affairs Agency
Title: Amend Uniform Rules, Create Educat
BRU: Legislative Council
Sponsor: Kerttula
Component: Session Expenses

EXPENDITURES/REVENUES: (THOUSANDS OF DOLLARS)

OPERATING	FY 91	FY 92	FY93	FY 94	FY 95	FY 96
Personal Services	0.00	0.00	0.00	0.00	0.00	
Travel	0.00	0.00	0.00	0.00	0.00	
Contractual	0.00	0.00	0.00	0.00	0.00	
Supplies	0.00	0.00	0.00	0.00	0.00	
Equipment	0.00	0.00	0.00	0.00	0.00	
Land & Structures	0.00	0.00	0.00	0.00	0.00	
Grants, Claims	0.00	0.00	0.00	0.00	0.00	
Miscellaneous	0.00	0.00	0.00	0.00	0.00	
TOTAL OPERATING	0.00	0.00	0.00	0.00	0.00	0.00
	0.00	0.00	0.00	0.00	0.00	
CAPITAL	0.00	0.00	0.00	0.00	0.00	
	0.00	0.00	0.00	0.00	0.00	
REVENUE	0.00	0.00	0.00	0.00	0.00	
	0.00	0.00	0.00	0.00	0.00	
FUNDING: (THOUSANDS OF DOL	0.00	0.00	0.00	0.00	0.00	
General Fund	0.00	0.00	0.00	0.00	0.00	
Federal Fund	0.00	0.00	0.00	0.00	0.00	
Other	0.00	0.00	0.00	0.00	0.00	
TOTAL	0.00	0.00	0.00	0.00	0.00	0.00
	0.00	0.00	0.00	0.00	0.00	
POSITIONS:	0.00	0.00	0.00	0.00	0.00	
Full-Time	0.00	0.00	0.00	0.00	0.00	
Part-Time	0.00	0.00	0.00	0.00	0.00	
Temporary	0.00	0.00	0.00	0.00	0.00	
	0.00	0.00	0.00	0.00	0.00	

ANALYSIS: (ATTACH A SEPARATE PAGE IF NECESSARY)

Prepared By: Senate HESS Committee
Division:
Phone: 465-3818
Date: 10-Apr-91
Approved By: Sturgulewski
Agency: Legislature
Date: 10-Apr-91

DISTRIBUTION (BY PREPARER)
LEGISLATIVE FINANCE
LEGISLATIVE SPONSOR

REQUESTOR Sturgulewski
OFFICE OF MANAGEMENT & BUDGET
AGENCY(IES)

FISCAL NOTE

No. 1
Bill Version: HCR 3
(H) Publish Date: 4/8/91

STATE OF ALASKA
1991 LEGISLATIVE SESSION

Revision Date:
Title: Proposing an amendment to... Uniform Rules... relating to Education comm... & H&SS comm...
Sponsor: Representative Carney
Requestor: House HESS

Department Affected: Legislative Affairs Agency
BRU: Legislative Council
Component: Session Expenses

COMPONENT SERIAL NO: 782

Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY 92	FY 93	FY 94	FY 95	FY 96	FY 97
PERSONAL SERVICES	0	0	0	0	0	0
TRAVEL	0	0	0	0	0	0
CONTRACTUAL	0	0	0	0	0	0
SUPPLIES	0	0	0	0	0	0
EQUIPMENT	0	0	0	0	0	0
LAND & STRUCTURES	0	0	0	0	0	0
GRANTS, CLAIMS	0	0	0	0	0	0
MISCELLANEOUS	0	0	0	0	0	0
TOTAL OPERATING	0	0	0	0	0	0

CAPITAL	0	0	0	0	0	0

REVENUE	0	0	0	0	0	0

FUNDING: (Thousands of Dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0
OTHER	0	0	0	0	0	0
TOTAL	0	0	0	0	0	0

POSITIONS:

FULL-TIME	0	0	0	0	0	0
PART-TIME	0	0	0	0	0	0
TEMPORARY	0	0	0	0	0	0

Estimate of current year impact:

ANALYSIS: (Attach a separate page if necessary)

Zero fiscal impact.

Prepared By: Pamela A. Stoops, Director Pamela A Stoops Phone: 465-3850
Division: Administrative Services Date: 3/7/91

Approved By: Warren W. Endicott, Executive Director Linda Fix for
Agency: Legislative Affairs Agency Date: 3/7/91

Distribution (by preparer): Legislative Finance, Legislative Sponsor, Requestor, OMB, & Impacted Agency(ies).

Alaska State Legislature

SENATE

Official Business

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

MEMORANDUM

TO: Senator Arliss Sturgulewski
Chair, Senate Health, Education & Social Services Committee

FROM: Senator Sam Cotten

DATE: March 11, 1991

RE: SCR 17 (Bone Marrow Donor Week)
SB 177 (Special Appropriation)

I have introduced SCR 17 and SB 177 in an effort to educate persons regarding bone marrow transplants and to provide funding for efforts to increase enrollment in the donor program.

SCR 17 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.

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.

For the committee's review, I have attached information concerning bone marrow transplants and the bone marrow donor program.

Dale Goodloe
testimony
(summary)

BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE ALASKA 99508 (907) 563-3110

March 12, 1991

Senate HESS Committee
Senator Arliss Sturgulewski, Chair
P.o. Box V
Juneau, Alaska 99811

TESTIMONY BEFORE THE SENATE 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 Marror 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 Senate HESS Committee's support for Senate Bill 177 and Senate Concurrent Resolution 17.

Respectfully submitted,

Dale V. Goodloe

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.

- 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.
- 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
	TOTAL EXPENSES:	$ 221,800

BUDGET DETAIL

1. PERSONNEL

			ANNUAL
Clerical Position:	20 Hours Per Week @ $9.50/Hr. 23% Fringe Benefits	$ 12,150	

Mailing out information packages, making appointments, reviewing medical history forms, typing labels & files, assembling information (consent forms, donor data forms, medical history forms, etc.), coordinating shipping, HLA data processing, data submission to National Bone Marrow Program (NBMP) representative, accounts receivable and payable, correspondence.

Phlebotomist:	8 Hrs./Wk. @ $13/Hr. 23% Fringe Benefits	6,650	

Draws blood specimen, labels tubes, prepares package for shipping.

Technical Coordinator:	12 Hrs./Wk @ $19.50/Hr. 23% Fringe Benfits	14,975	

Provides information session for potential donors, determines eligibility for program, oversees drawing and shipping of specimens, coordinates HLA data and enrollment in National Bone Marrow Program.

	TOTAL PERSONNEL		$ 33,775

2. TRAVEL

Technical Coordinator:	2 Trips Wk./Avg. 20 Miles Roundtrip X 26 Cents/Mile	$ 550	
Phlebotomist:	1 Trip Wk./Avg. 14 Miles Roundtrip X 26 Cents/Mile	275	
	TOTAL TRAVEL		$ 825

5. OTHER EXPENSES

	ANNUAL
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**

3. EQUIPMENT

(One Time Purchase)

		ANNUAL
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:

- All coordinating site selection and organization for remote draws is done from Anchorage.
- Volunteers are available at the remote site to coordinate activities and times.
- 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).
- 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).
- A minimum of 50 residents are interested in enrolling in the program, with a maximum of 100 per day.
- 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

Technical Coordinator:	16 Hrs. Coordinating/Site; 12 Hrs. At Each Site; 6 Sites - 168 Hrs. X 19.50 + 23% Fringe Benefits	$ 4,040
Clerical:	12 Hrs./Site X 6 Sites - 72 Hrs. X $9.50 + 23% Fringe Benefits	850
Phlebotomist:	12 Hrs./Site X 6 Sites - 72 Hrs. X 313 + 23% Fringe Benefits	1,160
	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

March 12, 1991

Senate HESS Committee
Senator Arliss Sturgulewski, Chair
P.O. Box V
Juneau, Alaska 99811

Dear Senate HESS Committee Members:

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 200 potential donors into the National Marrow Donor Program in the past six weeks. Attached is my "Gift of Life" letter which we are using in our recruitment efforts.

We need your help now. Senate Bill No. 177 and Senate Concurrent Resolution No. 17 provide funding for the Blood Bank of Alaska to recruit an additional 3000 Alaskan marrow donors. This funding will cover one-time start-up costs to expand the Blood Bank's 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.

I would appreciate the Senate HESS Committee's support for Senate Bill No. 177 and Senate Concurrent Resolution No. 17. Thank you for your consideration.

Sincerely,

Eileen L Albert

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

THE FOLLOWING PAGES
WERE TREATED AS A UNIT
IN THE ORIGINAL FILE

Sen. Sturgulewski

BLOOD BANK OF ALASKA, INC.
4000 Laurel Street
ANCHORAGE, ALASKA 99508
(907) 563-3110

Dale V. Goodloe
Operations Manager

BLOOD BANK OF ALASKA, INC.

4000 LAUREL STREET • ANCHORAGE, ALASKA 99508 • (907) [illegible]

March 11, 1991

Senator Arliss Sturgulewski
Senate
P.O. Box V   Capitol, Room 427
Juneau, Alaska 99811

Dear Senator Sturgulewski:

Enclosed you will find information about our efforts to recruit Alaskans as bone marrow donors.

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 200 potential donors into the National Marrow Donor Program in the past six weeks.

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I would appreciate your support for Senate Bill No. 177 and Senate Concurrent Resolution No. 17. Thank you for your consideration.

Sincerely,

Eileen L. Albert

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

Sample forms
used in our
donor drives

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

3/4/91

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.

MEMBER OF AMERICAN ASSOCIATION OF BLOOD BANKS
MEMBER OF COUNCIL OF COMMUNITY BLOOD CENTERS

BLOOD BANK OF ALASKA, INC.
4000 LAUREL STREET • ANCHORAGE, ALASKA 99508 (907) 563-3110

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

MEMBER OF AMERICAN ASSOCIATION OF BLOOD BANKS
MEMBER OF COUNCIL OF COMMUNITY BLOOD CENTERS

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 is 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

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

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

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

MEMBER OF AMERICAN ASSOCIATION OF BLOOD BANKS
MEMBER OF NATIONAL CLEARINGHOUSE PROGRAM

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 catergories, you are at high risk of contracting the disease:

- 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.
- Past or present abusers of intravenous drugs.
- Males who have had sex with another man, even one time since 1977.
- 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).
- Individuals with Hemophilia or related clotting disorders who have received clotting factor concentrates.
- 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.
- Persons who have had, or been treated for, syphilis or gonorrhea (Clap, the Drip, Strain, Louies, Bad Blood) during the preceding 12 months.
- 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 exhange 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( ) <u>MALES:</u> Have you had sex with another man since 1977 (even one time)?
    Y( ) N( ) <u>FEMALES:</u> 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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CONSENT TO JOIN A VOLUNTEER MARROW DONOR REGISTRY

SUBJECT'S STATEMENT

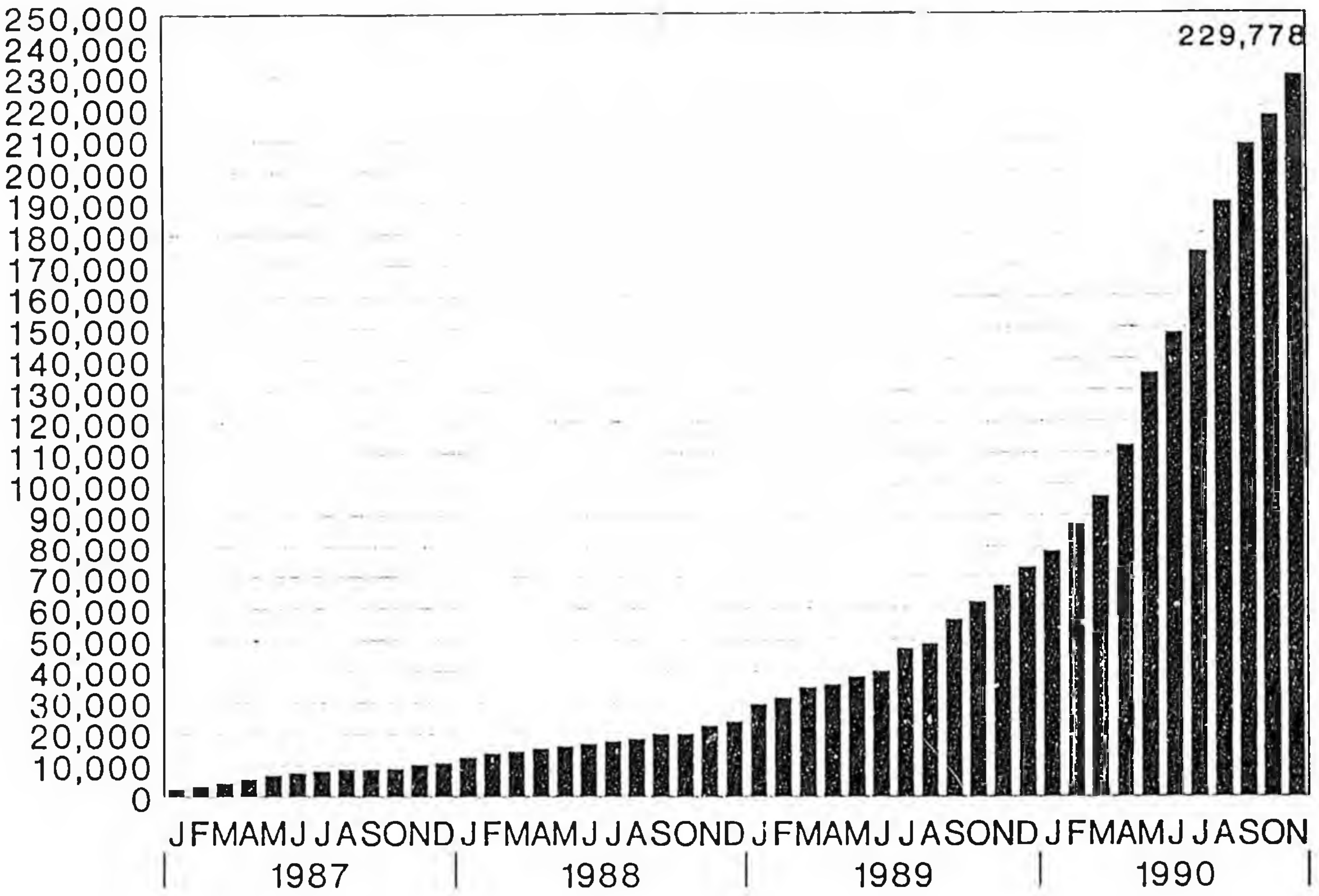
You may perform HLA typing on a research blood sample drawn from me. I agree to allow my name, HLA typing information, and results of any virology testing to be placed into a local registry at the Blood Bank of Alaska and also at Puget Sound Blood Center. I understand that my HLA type, but not my name, 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

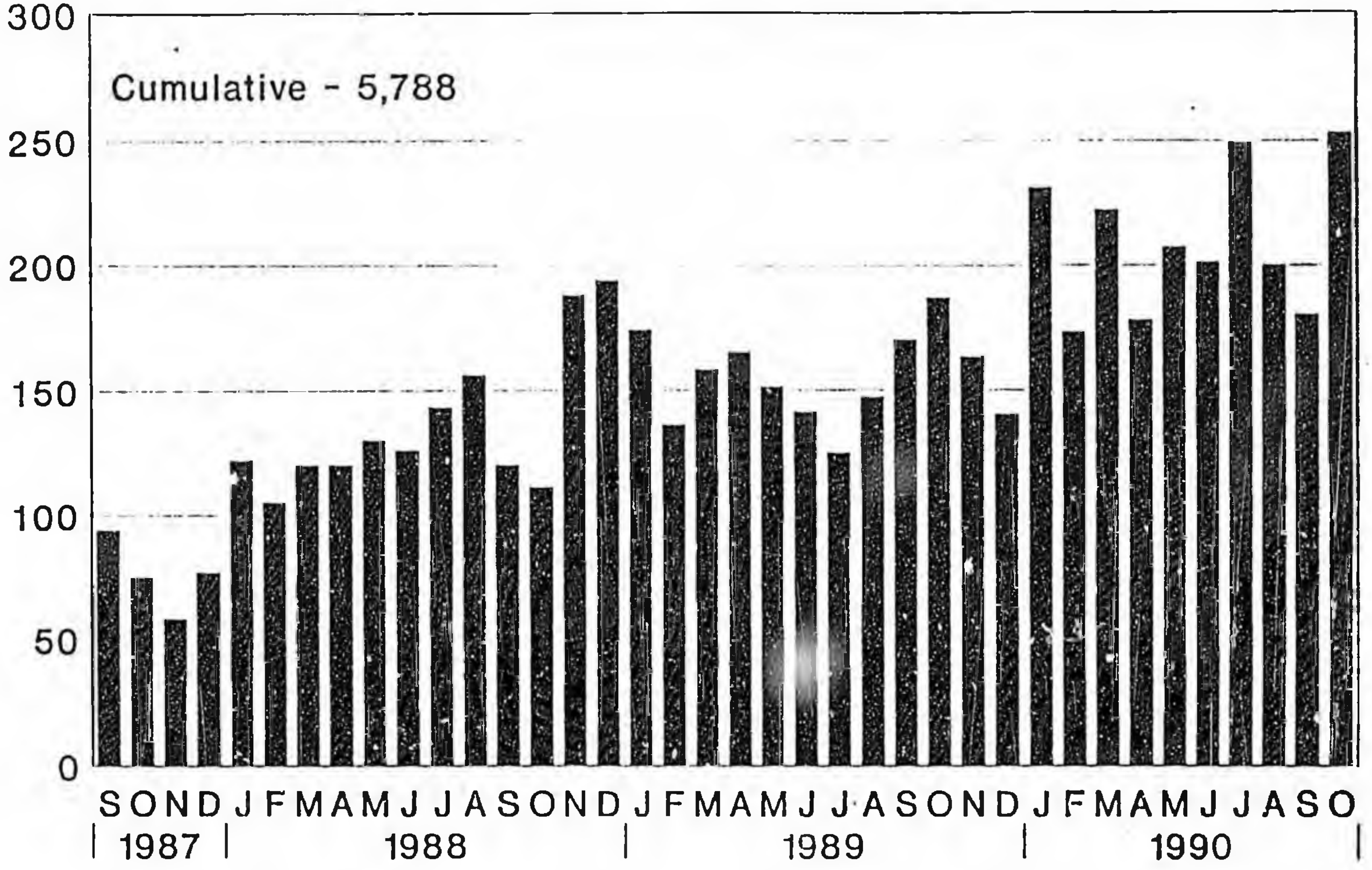
VOLUNTEERS WILLING TO DONATE MARROW



Source: National Marrow Donor Program
November 17, 1990

PRELIMINARY SEARCH REQUESTS

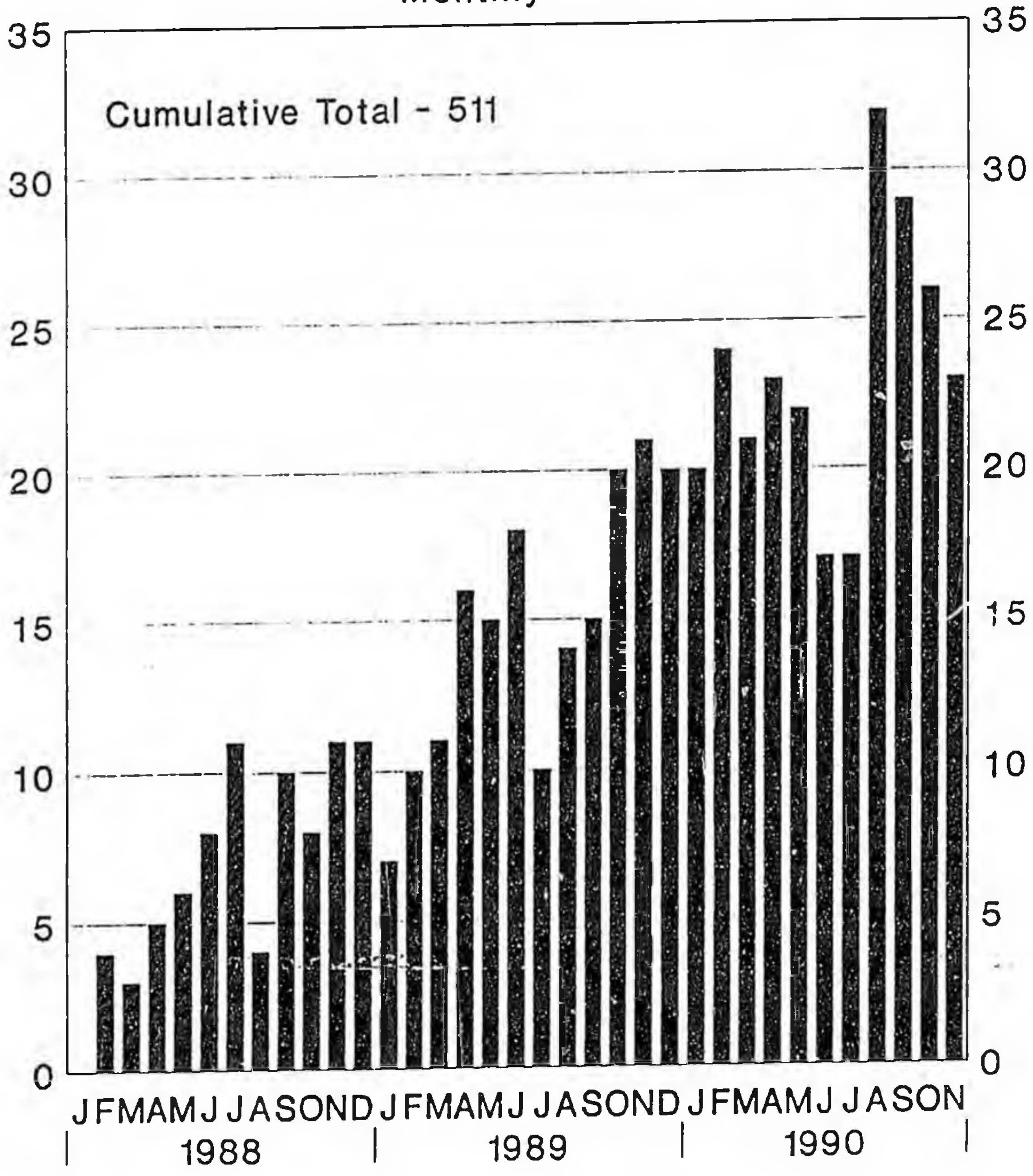
By Month Initiated



Source: National Marrow Donor Program
November 1, 1990

NMDP SEARCHES REACHING TRANSPLANT

Monthly



Source: National Marrow Donor Program
November 20, 1990

THE WHITE HOUSE

Dear Friends,

It is a pleasure to send this message of gratitude and encouragement to all those who are responding to the need for more volunteer bone marrow donors throughout our country.

Today, because of the generous spirit of hundreds of thousands of Americans, many patients with fatal blood diseases have received the chance of a lifetime. This spirit has now traveled to many other countries as well, thus providing a larger pool of volunteer donors and a sense that this world is a little bit better because strangers are giving the living gift of marrow. But so many more people are still on waiting lists, hoping and praying that someone will donate marrow that matches their own. The National Marrow Donor Program is making it possible to build this worldwide network of hope and help.

I salute everyone who is participating in donor recruitment efforts. May your commitment bring each of you a sense of satisfaction that you are part of a global lifesaving effort.

Warmly,

Barbara Bush

LIFESTYLES

MONDAY
SECTION C March 11, 1991

THE QUEST FOR MARROW

[illegible]

Marrow donor Doris Moody: The pain was "very minimal," she says.

Leukemia patient Eileen Albert: "I would rather spend my time living than waiting to die."

By DONNA FREEDMAN
Daily News reporter

Donor happy to help save a life

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

Please see Page C-2, DONOR

By DONNA FREEDMAN
Daily News reporter

Cancer patient finds a cause

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. 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 20,000.

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 18,000 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

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, 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.

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

Albert speaks about these things in a calm, matter-of-fact way. Her audiences — whether the Eagle River Lionesses 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 164 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 $8,100 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 Cotten, 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, 11901 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."

Wasilla grows B2 ☐ Ice sculpture B7

METRO
The Anchorage Times

SUNDAY
March 3, 1991

Leukemia victim fights odds in donor hunt

Photo for the Times by EVAN R. STEINHAUSER

Leukemia victim Eileen Albert, center, shown here with husband, Steve, and sons Mathew, lower left, and Kyle. Albert is looking for a bone marrow donor.

Five-country search finds no perfect match

By PATRICIA SOLOVEICHIK

TIMES WRITER

Experts said leukemia victim Eileen Albert had a 1-in-20,000 chance of finding a bone marrow donor who could save her life.

But more than 350,000 searches and $6,000 later, the Eagle River woman still waits for her chance.

Albert has checked bone marrow registries in the United States, France, England, Canada and Israel. She has found 13 possibilities but no perfect match.

Yet she considers herself fortunate because she has a form of leukemia that is curable with a bone marrow transplant and because she was diagnosed early.

Perfect matches are rare, and at age 37 she is considered "middle-aged" for a transplant.

"I need to have a transplant before I'm past my 40s, when the success rate drops," she said. "And any day I could go into blast crisis."

"Blast crisis" is the point at which the bone is overpacked with abnormal, immature white cells. The overcrowding occurs when "supervising cells" recognize the immature cells, then order the creation of more white cells, which are also immature. Any existing healthy cells are crowded out.

"It's total system shut down, rapidly fatal and essentially irreversible. They don't do transplants during blast crisis. It's the end; that's what it is," Albert said.

She said the timing of blast crisis is "totally unpredictable. It could happen tomorrow, but the average is three to five years. I feel I have some time here and I'm counting on that."

Albert, who has two children, quit her job as a school nurse at Fire Lake Elementary in Eagle River to "take better care of myself."

"I don't really think 'what if we don't find someone,' " Albert said. "I may have gotten a clue that

See Bone, page B3

Bone

Continued from page B1

> 'I may have gotten a clue tha[illegible]y end may be sooner than most, but I'm not living to die. I just live.'
>
> — Eileen Albert, leukemia victim

my end may be sooner than most, but I'm not living to die. I just live."

She was diagnosed with leukemia in September when she was hospitalized for minor surgery. Abnormalities were found in her blood tests.

None of Albert's family has matching bone tissue that would enable a transplant, said Dale Goodloe, operations manager of the Blood Bank of Alaska Inc., which is affiliated with the National Bone Marrow Donor Program. Her 2- year-old son Kyle was the closest match.

Only one-third of those people needing a bone marrow transplant find donors within their family. The other two-thirds must look to non-relatives for that gift, Goodloe said.

"I've never been really sick or had many personal needs. And now I find that my life is in the hands of a perfect stranger," Albert said.

There are about 250,000 people willing to donate marrow. About 10,000 people nationwide are awaiting transplants at any given time.

There is about a 1-in-20,000 chance of finding a perfect match for Caucasians. The chances for minorities fall as low as 1 in a million, depending on race, Goodloe said.

Alaska has about 150 people needing a bone marrow transplant, and 22 people are added to that list every year, he said. There are only a handful of Alaska Natives in the registry.

"This is one of the fatal diseases that actually has a cure. Without the bone marrow transplant, these people are going to die. That's a given," Goodloe said.

But the number of donors is far too low to match more than 500 of those 10,000 people per year. Depending on how early the disease is diagnosed, the patient may have as many as five years or as few as six months to live.

A perfect match is a rarity at this point.

Goodloe said the expense of the tissue typing is the reason for the inadequacy of the national bone marrow donor list. Without government funding, few organizations can afford to collect and type large numbers of samples.

"It's a delicate balance. Donors are more important than money, but without enough money, the donors can't help any one," he said.

The Blood Bank of Alaska is trying to get $300,000 from the state for a program that would bring in 3,000 donors per year. Goodloe also is trying to gain corporate sponsorship, asking businesses to pay the $56 apiece for employees willing to donate a blood sample.

Albert, who has paid $6,000 of her own money for sampling costs, is getting some community help. BP Exploration (Alaska) Inc. has agreed to pay the $56 sampling cost for at least 100 of its employees. The Lions Club of Eagle River has donated $5,000 and the Lioness Club, also of Eagle River, has donated $500.

The samples are sent to the University of California at Los Angeles laboratory for tests to determine the HLV type (human lucocite antigen) of the white blood cells. Six key antigen types are determined from a blood sample and coded, Goodloe said. These numbers are used for matching the donor to the recipient.

"There is no perfect match. This is like DNA. It's your genetic code. But the six matching antigens are key to getting the body to accept the bone marrow," he said. A rejection of the tissue would mean death for the patient, he said.

Without funding, the Blood Bank is asking donors to pay as much of the testing costs as possible. If they can't afford it, other funding will be found, he said.

"We just don't want to get more donors than we have money for testing. We know that the minute we ask people to help, donors will not be hard to find. But we don't have the money to pay for the tissue testing right now," he said.

Medical insurance pays for the estimated $180,000 procedure and expenses of the donor and the recipient, but the initial match must be made with private funds, he said.

A matching donor is flown to Seattle's Fred Hutchinson Cancer Research Center to donate the bone marrow. Under either general anesthesia or a local anesthetic, bone marrow is drawn through needles from the pelvic bone.

No cutting is involved, but a hospital stay of about two days is necessary. The body replaces the marrow in two to three weeks, Goodloe said.

Doris Moody, a 50-year-old Anchorage homemaker who donated bone marrow recently, said the procedure is short and painless, with some soreness for about a week afterward.

"I feel really good about it. The discomfort shouldn't scare anyone. I would feel privileged to do it again," she said.

The patient receives the marrow as a sort of blood transfusion that makes its way through the body to the bones.

In preparation for the procedure, the recipient must undergo painful and extensive chemotherapy and radiation, which kills all the existing bone marrow to prepare for the new marrow, Goodloe said.

The transplant has a 48 percent success rate, but patients live for years with the uncertainty.

Bone marrow donor forms can be picked up at the Blood Bank of Alaska and at the Eagle River Cancer Society. Blood typing for the donor program is done each Monday from 8 a.m. to noon at the Blood Bank.

A special blood typing drive was scheduled for Monday from 4-6 p.m. at the Cancer Society.

Local woman uses own illness as vehicle for helping others

Fire Lake Elementary School nurse and Eagle River resident Eileen Albert is in need of a bone marrow transplant to cure her of chronic myelogeneous leukemia. Because her tissue type is not matched by any of her relatives, she is seeking an unrelated marrow donor locally and nationally with the assistance of the National Bone Marrow Donor Program. Local donor drives, conducted by the Blood Bank of Alaska and Eileen's friends, are forthcoming. STAR PHOTO BY DON ALEXANDER

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By DON ALEXANDER
Of The Star Staff

Today is Eileen Albert's thirty-seventh birthday. Another year has come and gone, and like most people, Albert doesn't concentrate on the passage of her life.

Unlike the majority of people, however, Eileen has a much firmer grasp on the finite nature of her life—she has a potentially fatal condition, chronic myelogenous leukemia.

Despite the seriousness of her predicament, Eileen is taking poet Dylan Thomas a step further; rather than merely "rage against the dying of the light," she urges those around her to transform almost certain death into a chance for life. And true to her profession as a registered nurse at Fire Lake School, even as she asks for help for herself, she does so for others.

CML, as Eileen's affliction is known, is a slowly developing kind of leukemia. Consequently, in her current "chronic" phase, Eileen feels little effect of the disease, other than a fatigue she once attributed to being a working mother. As the level of immature white blood cells being manufactured by her bone marrow increases, Eileen will go into a "blast crisis." This is when 30 percent or more of her white blood cells are immature. Those deformed cells will pack her bone marrow until it ceases to function and Eileen will die. The blast crisis could come tomorrow, she said, or it could come 10 years or more from now. The average is 3½ years from diagnosis — September 1990 was when she learned of her sickness.

CML can be cured with the assistance of family, sometimes, and most often, as it will have to be in her case, the assistance of strangers. The assistance needed is in the form of a blood marrow transplant.

Unfortunately, not just anyone's blood marrow will do. When an exact match of Human Leukocyte Antigen of a potential donor is not found among the victim's closest relatives, a match is sought from unrelated donors. HLA is the "tissue type" of a person. It is found in the genetic "markers" on white blood cells. A perfect match, which is usually the only kind acceptable from an unrelated donor, involves matching 6 of 6 markers.

An acceptable match for a related donor, and sometimes for unrelated donors, is 5 of 6. The closest Eileen came to a match with a relative was 4 of 6 with her son Kyle, 2. Her other son, eight-year-old Matthew, and her husband Steven, did not even come that close.

Siblings are most often where related donor matches are found. While Eileen's two brothers matched each exactly, they were far from matching her.

As can be expected, the chances of finding a stranger whose hereditary makeup is similar to one's own is very low. The odds of doing so range from 1:10,000 to 1:100,000.

To help find unrelated donors, a National Marrow Donor Program was established in 1987. Originally projected adequate at 100,000, the size of the donor registry needed has grown to 500,000 or more. Currently, half that number is available. The national donor program has become a cause of personal need and personal satisfaction for Eileen.

"I don't dwell on thinking about my own death," Eileen explained. "The saddest thing about thinking about that is just the thought of being without my family. And that's another reason why I want to fight this.

"But it's because I don't feel physically ill (that) I feel like I have an opportunity that I can't miss," she continued. "That opportunity is to let people know about this and encourage them to become donors.

"It's a challenge of my lifetime and an opportunity for all the rest of you."

In addition to seeking a marrow donation through the national registry, much local help has been forthcoming, Eileen said.

The "network" of school nurses and staff in the Anchorage School District has provided help, as has Steven's professional compadres at the Alaska Department of Fish and Game. Her church has also assisted.

Dale Goodloe, operations manager of the Blood Bank of Alaska, is helping establish donor drives. While the drives are specifically for Eileen, volunteers' HLA types are added to the national registry. Because some 9,000-10,000 people may be seeking donors at any given time, and many of those may be in the final stages of their disease, locally generated donor tests are not screened here, Goodloe said. Consequently, Eileen will receive donor information from the national registry.

This arrangement brings with it several benefits for Eileen and the cause in general. First of all, it was the basis for contracting with the UCLA Medical Center to do HLA testing for donors at a substantially reduced $50. That price is from 33 percent to 150 percent cheaper than if a private physician were to conduct a single HLA typing.

Also, because of the addition of the donors' types to the national registry, the national program contributes matching funds against those raised locally for conduct of HLA testing for Eileen's marrow transplant.

For prospective donors of bone marrow for Eileen and others, and actual donors, the process is one of minor inconvenience.

Those wishing to donate fill out a few forms, including a medical history. They are informed of every aspect of what they wish to do, including risks. A single blood sample tube is filled and the sample, in Eileen's case, is shipped to UCLA.

The sample is tested and the HLA type is added to the national registry. If a specimen matches Eileen's HLA type, another sample will be taken to confirm the match. The donor and his or her family then attend an educational meeting at the Blood Bank of Alaska in Anchorage.

If everything is satisfactory, an appointment will be made for the donation to take place at the the Virginia Mason Hospital in Seattle. All expenses, with the exception of lost work time and child care, will be paid by Eileen's insurance.

The donation is made by "aspiration" of the liquid bone marrow with hypodermic syringes. There is no cutting. Nonetheless, the procedure, which will remove 3-5 percent of the donor's total bone marrow, is done under general anesthesia.

The procedure lasts 45 minutes to an hour. The aspirations are done from the area of the pelvis and produce soreness and bruising for about 3-7 days.

"They said it's as if you had . . . taken a real bad fail on the ice," Eileen said.

The risks of the procedure to the donor, which are minimal, are those normally associated with a routine surgery, such as those related to use of anesthesia. Of more than 2,000 donations completed, there has been no fatalities of a donor.

Because of the pain, donors usually spend one or two nights in the hospital. Donors replace the donated bone marrow in a couple of months.

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On the other hand, the bone marrow transplant procedure is fraught with suffering and danger for the recipient.

When a donor has been found for Eileen, she will undergo about a week of intensive chemotherapy and irradiation treatment at the Fred Hutchinson Cancer Research Center, about a block away from the donor's hospital. This procedure will kill all her existing bone marrow. It is also the "point of no return."

While there are many chances for a potential donor to back out, and legally, could do at this point in the procedure, there is a moral obligation to continue; if a transplant does not occur at this point, Eileen will not survive.

Once Eileen's bones has essentially become empty, the transplant takes place. This process, similar to a blood transfusion in form, marks "Day 0."

For the next two-to-three weeks, "it's kind of a critical period of time to see if the bone marrow cells make their way into" the bone marrow cavities and start reproducing, Eileen said. Numerous blood tests are conducted to monitor the progress of the transplant. If and when the marrow graft appears to have "taken," Eileen will be considered to have passed the first, and one of the most difficult, hurdles.

During this entire period, Eileen will remain in a sterile environment called a laminar airflow room. It is similar to the "boy in the bubble" situation because of the patient's almost non-existent immunity to any bacterial and viral attacks.

If after about 30 days Eileen's white blood cell count indicates the graft is successful and the marrow is producing white blood cells, she will be allowed to move to an apartment near the hospital. Her newfound freedom will be dubious at best.

Required to report to the hospital daily for more blood tests, she will also have to wear a mask and protective clothing whenever she leaves the apartment. While her family can be with her, this period will last from two to three months.

At the 100 day mark, if all is going well, Eileen can be released. Despite her medical release, she will still be vulnerable to the point where work is probably out of the question for at least a year.

Eileen can encounter a number of difficulties with the transplant. As well as the possibility the graft will not take hold, and her susceptibility to disease, there is also a chance she will suffer "graft-versus-host disease." This condition, Eileen said is "where the bone marrow that you have gotten kind of wakes up and says, 'Hey, I'm in the wrong body.'

"It's not my body rejecting the bone marrow. It's the bone marrow rejecting me," Eileen explained. "It sets up infections and inflammations that are hard to control."

The long road ahead takes its toll on Eileen, to the extent that she is experiencing emotional ups and downs. Her optimism is buoyed though "by the energy that I'm getting from other people wanting to help and do things. And the sense of hope that comes from that is wonderful."

". . . It makes all the time from now until then more special, and all the more valuable to use in constructive, happy ways."

At the same time the CML struggles to rob her of her life, Eileen finds strength is a new sense of purpose.

"'Even if it doesn't help me, ultimately, the fact that it will have helped somebody is comforting to me," she said. Additionally, because she has the resources that many lack in the form of insurance, she implied that working to gain donors seems especially to be the right thing to do. This is brought home even stronger by the uncertainty of how long she has left.

"Because I've been told that I do have an end point that's relatively soon, it makes all the time from now until then all the more special," she said, "and all the more valuable to use in constructive, happy ways."

"The bottom line is I need everyone's help," Eileen said. "I mean, my life is in the hands of whoever may come forward and be that unrelated donor. By myself, I can't do it.

"We know this is a shot in the dark kind of thing, 1 in 20,000. But you never know. It could be the next person who has their blood drawn," she said.

According to Goodloe, the only thing holding up donor drives for Eileen is money for the HLA testing. The money had been raised was mostly consumed by the testing of the 100 prospective donors who signed up at two local schools as a result of personal knowledge of Eileen's plight.

Currently, Goodloe is seeking a corporate donation which may solve the problem. Despite this, they are asking for individual donations of any size and, if possible, they would like prospective donors to pay for their own testing. Regardless, he stressed that no one should decide to forego joining the program because of an inability to pay for the testing. Donors are needed more than the testing fee.

They project getting between 100 and 200 donors per drive, he said.

Goodloe said he hopes the first donor drive can take place during the week of Feb. 25. Exact times and dates of drives will be announced in the future.

Those who do not wish to wait for a donor drive, or at any time decide to become a marrow donor, can do so at the Blood Bank of Alaska, located at 4000 Laurel Street in Anchorage.

Prospective donors must be between 21 and 55 years old and be in good health. The latter requirement includes an absolute freedom from HIV and AIDS infection and risk.

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BusinessWeek

OCTOBER 8, 1990 A McGRAW-HILL PUBLICATION

Personal Business

Health

A CHANCE TO SAVE THE LIFE OF A STRANGER

A year ago, Danny Storey, an Air Force equipment specialist in Milwaukee, agreed to donate bone marrow to a leukemia victim he had never met. The transplant was successful. Says an ecstatic Storey: "You're not giving up anything from yourself, but you have saved somebody's life."

Storey is one of 200,000 people who've joined the three-year-old National Marrow Donor Program (NMDP), which matches victims of fatal blood diseases with unrelated donors. The odds of finding a match is remote—just 20,000 to 1, which is why only 430 such transplants have been made so far. Still, those odds improve as more donors sign up. Corporations are joining the effort. In July, General Mills and Searle announced employee programs: The companies will pay the $75 cost of "typing."

Anyone from 18 to 55 and in good health can undergo this first step. An NMDP-affiliated blood bank or hospital will type your blood for basic human leukocyte antigens. The information is stored until you're given a preliminary match with a recipient, which could take years. There's a less than 20% chance you'll be called at all.

MANY TESTS. If you are, you undergo additional compatibility tests, a complete physical exam, and psychological counseling. "You know you're giving a specific person the only chance at life he has," says Tony Steele, coordinator of the NMDP at Belle Bonfils Memorial Blood Center in Denver. So far, over 50% of the recipients have survived.

If you feel you can't take it, this would be the time to back out. That's because the next irrevocable step is for the recipient to undergo rigorous chemotherapy aimed at destroying bone marrow so it can be replaced with yours.

Donating marrow is not simple. You are placed under general anesthesia while the marrow is extracted from your pelvic bones. Expect an overnight hospital stay and to ache for about 10 days.

The marrow, meanwhile, is rushed to the recipient for transplant within 24 hours. You'll know only the patient's first name and age, but you'll be kept informed about his or her status. Once the procedure is completed, however, the two of you can exchange names and even meet. The family of one leukemia victim who died actually listed his donor among his survivors.

Because of the emotional impact, the NMDP (800 654-1247) initially limited people to one donation, but it's reconsidering. That's because of donors such as Maria Gaitan-Endres, a property manager in McLean, Va. She gave marrow to a 33-year-old West Coast leukemia victim in August. The outcome is still in doubt, but she found the experience so rewarding that "I'd give again in a heartbeat."

Sandra Atchison

BONE MARROW RECIPIENT JAY GIBSON AND DONOR DANNY STOREY

PHOTOGRAPH BY MICHAEL L. ABRAMSON

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An estimated 16,000 children and adults are stricken each year with leukemia, aplastic anemia or other blood-related diseases. For many, the only hope for survival is a marrow transplant. Of the thousands who could benefit from a marrow transplant, nearly 70 percent cannot find a suitable match within their families. These patients need to find unrelated donors — people willing to come to the assistance of someone they likely will never meet. As the pool of potential marrow donors increases, so do the odds of survival for the thousands of patients in need. The chance that a patient will find a matching unrelated donor in the general population is between one in one hundred and one in a million. Since tissue types are inherited, and different tissue types are found in different ethnic groups, the chances of finding an unrelated donor vary according to the patient's ethnic background. A large file of potential donors, including Caucasians, African-Americans, Hispanics, Asians and Native Americans, would meet the needs of many of the patients who need a marrow transplant. Clearly, hundreds, perhaps thousands of lives could be saved if more people added their names to the list of potential marrow donors. The requirements to be a marrow donor are few. Unrelated marrow donors must be between 18 and 55 years of age and be able to pass a thorough physical examination. No special diet or physical program is necessary. Following are answers to commonly asked questions about marrow donation and transplants.

NATIONAL MARROW DONOR PROGRAM

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Minneapolis, MN 55413-1762

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DOW

THE LIVING GIFT OF LIFE

Becoming a Marrow Donor

What is the National Marrow Donor Program (NMDP)?

To meet the need of the thousands waiting for marrow transplants, the NMDP maintains a computerized data bank of available tissue-typed marrow donors nationwide. Established in 1987 as a collaborative effort of the American Association of Blood Banks, the American Red Cross and the Council of Community Blood Centers, the non-profit NMDP enables the efficient sharing and searching of information to join possible donors with patients in need of marrow transplants. The NMDP operates under a contract with the National Heart, Lung and Blood Institute of the National Institutes of Health.

What are the odds of a successful transplant?

While a number of factors influence the success of each individual case, replacing diseased marrow with new, healthy marrow increases the odds of long-term survival from less than 20 percent to between 45 and 80 percent.

How are donors and recipients matched?

Matching donors and recipients is a multi-step process. First, a blood test is performed to identify a person's Human Leukocyte Antigen (HLA) type or "tissue type." Once the HLA-type is known, this information is then entered and maintained in the NMDP data bank. When a data bank search identifies a match, the individual is contacted for additional tests and to make a final decision about becoming a marrow donor.

Can you change your mind about becoming a donor?

The answer is yes—potential donors have the *legal* right to withdraw at any time. However, once a match has been made and the patient has started the radiation or chemotherapy treatment required for the marrow transplant, there is no turning back. At that point, there is a moral obligation to proceed, as the patient would almost certainly die without the transplant.

How is the marrow removed?

Marrow, a jelly-like tissue, is collected during a hospital procedure which is performed under general or spinal anesthesia. The procedure generally lasts about 45 minutes. Using a needle and syringe, approximately three to five percent of the donor's marrow is extracted from the pelvic bones at both sides of the lower back area. Typically, an overnight hospital stay is advised. Within two to three weeks, the donor's body naturally replaces the donated marrow.

Does it hurt?

Donors typically experience discomfort and tenderness for a day or two. While it varies from person to person, most donors are back to their usual routines after a few days.

What are the risks?

To date, no donors have experienced any long-term adverse effects; yet, as in any medical procedure, a certain amount of risk exists, primarily associated with the anesthesia. However, the risk is very low.

Who pays for the procedure?

All costs associated with the marrow donation are charged to the recipient or the recipient's insurance company. Some donor costs, such as the initial HLA-typing, child care or loss of salary during the marrow donation procedure and recovery period may not be covered.

When does the patient receive the donor's marrow?

After the marrow is collected, it is immediately transported to the patient's hospital. Depending upon the circumstances, the patient will either receive the marrow immediately or after it has been processed to better prepare it for transplantation. The patient receives the marrow transplant intravenously, in a procedure similar to a blood transfusion. During the transplant, the patient experiences virtually no pain.

Do donors and recipients ever meet face-to-face?

Generally, donors do not meet their marrow recipients. Donors are told about the recipient's condition at the time they agree to donate and are welcome to contact the Coordinator for updates on the patient's progress. After the recipient has been discharged from the hospital, if both parties independently wish to communicate, the donor and transplant centers can help coordinate arrangements.

One more question…Why donate? This can be answered only by each individual. There is no monetary reward, no plaque or medal. There simply is the personal satisfaction of giving another human being the living gift of life.

For additional information about registering to become an unrelated marrow donor, please call the Coordinator at the nearest Donor Center. A list of participating Donor Centers with Coordinators' names and phone numbers accompanies this brochure.

Questions and Answers About Marrow Transplants

The Chance of a Lifetime

National Marrow Donor Program
1-800-654-1247

A collaborative effort of
American Association of Blood Banks
Council of Community Blood Centers

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

The Chance of a Lifetime

Our National Marrow Donor Program (NMDP) has been built through the efforts of many "determined moms and dads" and other family members, seeking not only to help their own loved one but other families in similar circumstances.

Despite the tireless efforts of these families, many of their loved ones never had "the chance of a lifetime" because a matched donor could not be found.

It is the memory of these patients which will continue to serve as the momentum for this Program.

E. R. Zumwalt, Jr., Admiral, USN (Ret.)
Chairman, Board of Directors
National Marrow Donor Program

The Discovery of a Lifetime

When doctors successfully completed the first marrow transplant in 1968, their discovery charted a new course for the treatment of leukemia, aplastic anemia and many other fatal blood diseases.

This breakthrough gave critically ill people an option they never had before; an option to fight for their lives and win. The long-term survival rate without transplant is zero to 15 percent; with a transplant it is 30-80 percent, depending on the disease.

Although this exciting new treatment brought hope to many, it brought disappointment to even more. Not because it didn't always work but because only about 30 percent of those who needed a transplant actually got one. Why? Because to receive a transplant you need a donor, one whose marrow matches yours.

Where do you find an exact double of you? If you're an identical twin, you can stop looking. If you're not, you can try your brothers and sisters. If there's still no match, you can move on to parents, then cousins, etc., but the odds at this point are against you. If you're adopted or an only child or have only half-siblings, finding a match has been almost impossible — until now.

Recent discoveries in classifying the characteristics of the immune system through the identification of human leukocyte antigens (HLA offer hope of identifying a matched donor who is an unrelated stranger.

The task of finding an unrelated donor that matches, however, is like finding a needle in a haystack. The odds of matching with someone else are estimated to be from one in one hundred, to one in one million. Even with those astounding odds, NMDP has found several hundred matches for patients and could find even more if its donor volunteer pool was larger. Each time a match is discovered, it offers the patient the chance of a lifetime.

Taking a Chance for Life

Marrow transplants are serious business and profoundly affect the lives of donors, recipients and their families. Those who choose to go through with it do so because they believe the chance for life is worth the risk.

When a patient and donor are matched, the first step is to educate the donor on the marrow collection process and risks involved. This is to provide the donor an opportunity to make an informed decision. Then the donor is examined to make sure the donor and marrow are healthy.

If all signals are "go," the donor waits until the patient is ready for the transplant. Sometimes, due to a patient's urgent condition, the preparations for marrow transplantation may go very rapidly. With other patients, the transplant date may be set two or three months in advance.

The patient begins chemotherapy and/or radiation treatment that virtually destroys his or her own marrow, killing healthy as well as diseased cells. This takes seven to ten days, after which the patient is ready to receive the donor's marrow through a transfusion.

This is when the donor enters the hospital — either the evening before or the morning of the procedure. Under general or spinal anesthesia, marrow is extracted from the back of the donor's pelvis. After being transported to the patient, the marrow is transfused directly into the patients' circulatory system. The marrow collection process itself takes about an hour. Generally, the donor stays in the hospital one night for observation and then goes home. The donated marrow (less than 10% of the body's supply) replenishes itself in a few weeks

For the patient, the transfusion of new, healthy marrow is the beginning of a long and slow recovery. About two weeks after the transplant, the first sign of success appears — an increase in white blood count. In four to six weeks the patient is ready to leave protective isolation and go to a regular hospital room, and from there, home. For those who reach the 100-day mark, the future is promising. For all patients, there is knowledge that they were lucky because they received the chance of a lifetime.

Real People Tell Their Stories

The National Marrow Donor Program is a network of Transplant Centers (who care for Patients), Donor Centers (who guard NMDP's volunteer donors' safety and confidentiality), Collection Centers (medical centers which meet NMDP's standard for marrow collection) and Recruitment Groups (which assist the NMDP in recruiting new volunteers for the National Registry; many NMDP Donor Centers are also aggressive recruitment arms of the NMDP).

Many patients, donors and transplant recipients have willingly told their stories so that others could also have a chance of a lifetime. The following are four stories which represent thousands of others who are hoping for or rejoicing about their chance of a lifetime. ◆

Today, thanks to the miracle of medicine and the gift of a stranger, these children have been saved through a bone marrow transplant. But so many people are on waiting lists, hoping and praying someone will donate marrow that matches their own. Not everyone can be a donor, but if you are one of those very special people, please volunteer today. To give your marrow is to give the gift of life.

Barbara Bush

Rae Lynn Offers Hope to Others

In July, 1988, Rae Lynn Geshick's doctors issued an appeal: a bone marrow donor for Rae Lynn.

Without a transplant, four year old Rae Lynn was expected to die within six months. An American Indian, she had been diagnosed with chronic myelogenous leukemia as a baby.

In 1988, there were only 18,000 volunteer donors on the NMDP Registry and no match for Rae Lynn.

The St. Paul Chapter of the American Red Cross, an NMDP Donor Center, worked cooperatively with the local Indian Health Boards. They asked for volunteer donors specifically from the local American Indian communities.

After three months of this special recruitment, a compatible donor was found and Rae Lynn had her transplant.

In February, 1990, Rae Lynn traveled to the White House to tape a Public Service Announcement with Mrs. Bush.

Rae Lynn and her foster parents, Lillian and Charles Bruehl, have responded many times to requests to tell Rae Lynn's wonderful story.

The Bruehls reported that Rae Lynn started first grade in the Fall of 1990. "She's doing super. Everything's going so great with her."

Rae Lynn tells her own success story.

"I'm the One Who Won the Lottery"

Larry Lundeen says he inherited his dedication to being a blood donor from his parents. He began donating blood when he was 18.

Next, Larry became a platelet or "apherisis" donor. "I know I'm doing something significant for someone else," he said.

Then, he heard about the National Marrow Donor Program. He wanted to join right away in 1987 when NMDP was just established.

In May of 1988, 120 days after joining the NMDP, he was called for more blood tests because he was a preliminary match; 60 days later, he received a call confirming that he was a match for a patient. "I remember the phone call. I knew where I stood and what I was doing. It was a thrill like you've just won the grand prize. I was elated."

Larry said he went through a series of physical exams and information sessions. "They wanted me to be properly informed." Thanksgiving week of 1988, his family traveled with him to the NMDP collection center. "We wanted it to be a family experience... My only anxiety was to keep it low key and not hear advice from everyone. I wanted it to be a personal, private experience."

Larry said offering the gift of marrow to a stranger "was one of the highest, best experiences in my lifetime. People should be standing in lines. I'm the one who won the lottery."

After several months, Larry was able to visit his recipient, Michael

A young father, Michael lived to celebrate his birthday in 1989 — with Larry as a guest. "Michael died four days after I left," said Larry. "I was surprised at how well I took the news. It didn't seem to depress me... but then his wife sent me the program from the funeral." Under survivors, after Micheal's wife and two kids, Larry was listed.

"I'd do it again for him or anyone else," said Larry. "It was awesome."

"We wanted it to be a family experience"

"The Risk is Minimal for the Feeling You Get"

Diana Dingwerth had signed up as a marrow donor four years before she received the call that she was a "miracle match."

She had originally volunteered because of a fellow employee's child who was seeking a donor.

"I had lots of reservations," said Diana. Each time Heart of America, her NMDP Donor Center, asked for another tube of blood to determine she was a full, compatible match, or offered more information, Diana said they asked her if she still wanted to go further.

"I finally decided I wanted to do it because someone might do it for my kids," she said.

Her miracle match was with an eight year old.

After being informed the marrow collection and transplant would be sometime in December, 1989, the transplant was moved up a month because of the condition of the patient. "I took Thursday and Friday off and went to the hospital Wednesday night. They took more tubes of blood but basically they let me rest," said Diana. The marrow was collected early Thursday and flown to the patient.

"The whole process was not as bad as I had imagined," said Diana. "I woke up with sandbags on my rear end. I could feel the weight but it did not hurt. I was groggy and a little dizzy."

"**W**hen I got home, it hurt to sit down or get up for about 10 days," said Diana.

Having had a sister with a liver problem which could not be helped, Diana said she felt a strong need to help someone else. "The risk is minimal for the feeling you get out of it. People treat you so well through this, it is not a scary thing. I'd highly recommend it."

"It hurt to sit down and get up for about 10 days."

"I have learned to say Thank You"

Patrick Williams started his sophomore year in college in the Fall of 1990. The following is his high school valedictorian speech.

Hello, my name is Patrick Williams. I am very pleased to be standing here tonight with this chance to address my class, our parents and friends, and our teachers. I am glad for the opportunity to convey my appreciation and thanks to Lebanon.

As most of you know, I came down with aplastic anemia in October of my sophomore year. I want to thank the teachers who noticed a change in my attitude, in my ability to think, and in my stamina. They called my parents and suggested that I see a doctor immediately.

In the Corvallis Hospital I learned the grim truth. I was lucky to be alive. Just months before, I was on the RKI Baseball Team that took second at State. The weekend before I had played in a tennis tournament with my brother. Now I had blood so weak it could barely support life. We left immediately for the Fred Hutchinson Cancer Research Center in Seattle.

The next day I learned there was no chance for a bone marrow transplant from my family. It was Saturday. That was the scariest day of my life. I want to thank my friends and their parents who called me and let me know Lebanon was as near as the phone. I want to thank those who drove up the next day — 5 hours to Seattle and 5 hours back. All we did was walk around a mall and goof off, but I was so grateful for friends to help take my mind off something so hard to understand. I felt fine and looked fine, but I had very little medical hope.

I spent three weeks in the hospital receiving a drug in hopes that it would stimulate my bone marrow to grow. The high school classes of '87, '88 and '89 flooded the hospital with cards, posters, flowers, and balloons. My walls could not be seen through the cards that covered them. I also want to thank all the people who supported my parents. Some even came to Seattle to visit them. I was very worried about them and glad they had friends to help them, too.

When I was released from Seattle, I came straight to Corvallis to see the Warriors play in the State playoffs at Parker Stadium. It was wonderful to be outside with my friends. Then it was home to isolation. I couldn't risk getting sick. I needed blood and platelet transfusions monthly, then weekly. I want to thank the Red Cross and the people in Lebanon who came out in force and donated blood in my name.

Finally, I needed blood every day. I entered the hospital in Corvallis to stay. My only hope was a 100,000 to 1 chance that Seattle could find a person with an exact match to my bone marrow. I felt fine and was active, but I was weakening. I wanted visitors constantly because I was more lonely than sick, and people came. Friends spent their whole Spring Break with me. We played countless hours of Pictionary and Nerf Basketball. It cannot be easy to visit a person in the hospital who is close to death, but you did it and I thank you.

I needed specific platelets every day now and they were getting harder to find. Once they had to be flown in from California. They almost came too late. I knew the doctor was preparing my parents. There is a fine line between hope and reality. But this story has a happy ending. The call came and they had found a donor. After a farewell party, we were off to Seattle.

The nurses say it is rare when a patient has support from his community that never lets up, month after month. But I had that support for four months in Seattle. The process defies explanation, but I am very thankful for the doctors, research scientists, and especially the nurses, that helped us through the whole process. These people have devoted their lives to saving people like myself. Thank you very much, Seattle.

I finally came home to a parade of friends. You saw me puffed up from medication, bald and ugly, but didn't turn away. To graduate with my class I had to stay home alone for the first half of my junior year and be tutored. I would like to thank my tutor for all her time, patience, and encouragement.

Now two years have passed. I am cured and my life is back to normal. Often people remark, the experience must have changed you forever. I wonder about that. How am I different?

I know how to use humor when things get tough. I understand about caring and community support. I appreciate others rather than judge them. We all do the very best we can with what we have. I take life slower and more easily. I have learned to take responsibility and say I'm sorry when I make a mistake.

I listen more and smile more. I treat my body well. I learned the power of a positive attitude. I like to be happy and I enjoy life.

And I have learned to say Thank You.

I want to thank one last person. Somewhere in this audience tonight, my donor's mother is sitting. Thank you very much for coming. You must be very proud of your daughter. I am glad you are here to share this moment with me. I am also glad you are here to see the wonderful people of Lebanon who, along with you and your daughter, helped me to live. Thank you.

A Special Plea for Minority Volunteers

We inherit our HLA-typing, or antigens, in the same way we inherit our skin color, eye color and hair color. This means the best chances of finding an HLA match are probably with someone who is from your same racial background. The National Marrow Donor Program is especially concerned that all American patients have an equal chance of finding a donor. This means we need people from America's minority groups to volunteer to give the living gift of life, offering both the patient and the donor the chance of a lifetime ◆

Questions and Answers

How Do I Become A Marrow Donor?

1. Give 2 Tablespoons of Blood

and consent to be entered on the National Marrow Donor Program Registry. (You must be 18-55 years old and in good health.)

2. Your Blood is "HLA-Typed"

at a medical laboratory to identify your antigens.

3. Your HLA-Type Goes in the Computer

The lab results are stored in the National Marrow Donor Program's main computer which is searched internationally on behalf of patients with fatal blood diseases.

4. A Preliminary Match is Determined

Only a small number of potential donors receive a call that they are a preliminary match.

5. Additional Blood Tests Are Requested

If you are a preliminary match, additional blood samples will be taken to determine if you are a precise match for a specific patient in need.

6. The "Miracle Match" is Identified

Special counselors will give you detailed information and a physician will assure that you are in excellent health.

7. You Make the Decision to Donate

After being fully informed, you make the decision to become a donor for a specific patient whose HLA type is the same as yours. ◆

What is marrow?

Marrow is found in the cavities of the body's bones. It produces blood components including white blood cells, the main agents of the body's immune system.

Who can donate marrow?

Volunteers must be between the ages of 18 and 55, in good health, and, if their HLA-typing matches that of a patient, the prospective donor must pass a comprehensive physical exam (done at no expense to the donor).

What happens if a match can't be found?

NMDP needs a larger registry of HLA-typed volunteers before it can find a match for the majority of patients seeking the gift of a stranger. For most patients who do not find a match, the end result is death.

If a match is found, what's next?

Once the laboratory tests have determined that a donor matches a patient, the next step is for the potential donor to decide whether to make the commitment to donate. NMDP volunteers are asked to make a clear choice after being fully informed about the procedure. Once a decision is made, the patient undergoes the treatment of chemotherapy and radiation. From that time until the transplant, the patient's life depends on the finality of the potential donor's decision.

How can a prospective donor make an informed decision?

Before making a commitment to donate, the NMDP volunteer who has been identified as a match for a patient, will talk with the NMDP donor center physician and the marrow collection team. Often, the prospective donor's spouse or other family members are also included in these conferences or review the extensive educational materials provided.

The marrow collection team at the hospital can also answer the prospective donor's questions. The prospective donor should know what to expect before, during and after the collection process.

After this information session, the prospective donor is asked to sign an intent to donate. By this point the donor needs to be certain about whether or not to go ahead and donate marrow.

The prospective donor must make both a psychological commitment and a commitment of time.

Can a matched potential donor say no?

Deciding to participate in a marrow transplant is a serious matter for all concerned. A potential donor who is successfully matched with a transplant candidate may decide not to go ahead with the process. There are legitimate reasons for saying "no," including illness, the amount of time involved, the risk, or even fear. Even in related donor situations, families sometimes decide against one family member donating to another. NMDP's participating centers ***always*** respect the individual decision of the matched volunteer.

What happens pre-donation for the donor?

While many of NMDP's donors have described the predonation time as exciting, it requires a heavy psychological commitment from the donor. A complete physical examination must be arranged to assure that the donation is as safe as possible for the donor. Sometimes, the physical exam identifies an otherwise undetected health problem, making the prospective donor unavailable to the patient. This often creates extreme disappointment for the prospective donor as well as the patient.

Those who do pass the physical are not asked to make any accommodations in diet, working or social habits prior to the marrow donation. And because they are volunteers in a very special life-saving process, donors are treated with very special care and respect by the medical team.

However, donors are asked to refrain from taking any unnecessary risk which could lead to illness or injury for the period when the patient is undergoing the pretransplant regimen. Doctors want both patient and donor to be in the best physical shape possible for transplant.

What's involved in removing the marrow?

All donors receive spinal or general anesthesia. Generally, four to eight tiny incisions are made in the back, pelvic area. The marrow is extracted through those incisions. This process generally lasts about 60 minutes. Less than 10 percent of the body's marrow is removed. Within a few weeks, the donor's body has naturally replaced the donated marrow.

Typically, the donor enters the hospital the day before or the day of the donation. Donors remain in the hopital for several hours or even overnight after the marrow collection. Donors can expect to feel some soreness in their lower back for a few days following the donation.

What are the risks to the donor?

To date, there has never been a donor fatality attributable to the collection process. That doesn't mean there aren't any risks, though. Because the donation process is painful, donors are given general or spinal anesthesia. Complications can result from anesthesia, including nausea or sore throat. The probability of a serious complication occurring cannot be accurately predicted but it is very low. ◆

What are the chances of actually matching a patient?

Doctors estimate that your chances are between 1 in 100 and 1 in one million of matching with another unrelated person. This means that you may never be called, even as a preliminary match. However, if you are identified as a match, you are quite possibly the only person who matches the patient seeking the chance of a lifetime through the NMDP. ◆

If I am a match, who covers my expenses?

All medical expenses relating to the transplant are paid by the patient's medical insurance. However, some donors may find it necessary to take unpaid time off from work or use personal vacation time. ◆

Who qualifies for a marrow transplant?

Marrow transplants are used to treat patients whose bodies cease to produce normal blood cells. About three-quarters of these patients have a cancer of the blood, such as leukemia. ◆

How do patients receive the marrow?

After the patient's own marrow has been destroyed through a rigorous treatment of chemotherapy and radiation, patients receive the marrow through a transfusion.

Once the donated marrow enters the patient's circulatory system through transfusion, it takes about two weeks to see the first evidence of a "graft." This means that the marrow has begun to work, producing new blood cells. A noticeable rise in the patient's white blood count is the first sign that a graft has occurred ◆

What complications does the patient experience?

Not all patients survive the rigors of the chemotherapy and radiation treatment. In addition, after the transplant, there are other complications which may result, including: non-engraftment, rejection, graft-versus-host disease (the marrow fights the patient's body), infection (the result of destroying the patient's entire immune system in preparation for transplant) and relapse (the original disease reappears in the marrow).

While doctors do not fully understand the causes of these complications, one thing is clear: any complications to the patient are not due to any fault of the donor's marrow. Before transplant, the donor's blood is examined and analyzed to ensure that the transplanted marrow is the best available.

For many patients, the gift of a stranger makes it possible for them to return to a disease-free life. For all patients, even those who experience complications, there is a grateful awareness that a donor offered them the chance of a lifetime.

Do the patient and donor know each other?

For many medical and psychological reasons, the donor and patient communicate only through the NMDP system for at least the first 100 days. If both the patient and donor wish to meet at a future time, NMDP coordinators may assist in the process.

A decision that's right for you?

Deciding to participate in the marrow transplant program is worthy of your most careful consideration. Through this brochure we have tried to introduce you to marrow transplantation and answer some of the most commonly asked questions from donors about the donation process. Because the HLA typing test is so expensive, NMDP encourages prospective volunteers to think carefully before becoming an NMDP volunteer. The facts are now in your hands and the decision is yours.

National Marrow
Donor Program
3433 Broadway St. N. E., Suite 400
Minneapolis, Minnesota 55413

THE PRECEDING PAGES
WERE TREATED AS A UNIT
IN THE ORIGINAL FILE

ALASKA School Nurses Association

April 18, 1991

Senator Arliss Sturgulewski
Senate
P.O. Box V
Juneau, Alaska 99811

Dear Senator Sturgulewski:

Enclosed is a copy of A Resolution Supporting Bone Marrow Donor Program Legislation, which was passed unanimously by our organization on April 12, 1991 at our annual convention.

The Alaska School Nurses Association, whose membership includes 100 school nurses throughout our state, thanks you for supporting SB 177 and SCR 17. Passage of this legislation will expand opportunities for Alaskans in both urban and rural areas to join this life-saving program. As more potential donors enroll, many individuals who need bone marrow transplants will gain new hope of having full, productive lives.

Thank you for your concern and support.

Sincerely,

Karen Sedlacek

Karen Sedlacek, R.N., C.P.N.P.
President, Alaska School Nurses Association
4837 Knights Way
Anchorage, AK 99508

A RESOLUTION SUPPORTING BONE MARROW DONOR PROGRAM LEGISLATION

BE IT RESOLVED BY THE ALASKA SCHOOL NURSES ASSOCIATION:

WHEREAS many Alaskans and thousands of people throughout the world suffer from leukemia and other blood-related diseases and cannot survive without a bone marrow transplant; and

WHEREAS recent advances in bone marrow transplants now give people dying of blood-related diseases hope to be cured if a donor can be found whose bone marrow matches their own; and

WHEREAS 70 percent of the individuals needing a bone marrow transplant lack a qualified donor within their own families and must find an unrelated donor whose bone marrow perfectly matches their own to provide the life-saving marrow; and

WHEREAS the chance of finding a suitable unrelated bone marrow donor is between one in 20,000 and one in 1,000,000, depending on the patient's genetic make-up; and

WHEREAS there is a national bone marrow donor registry, established in 1987, to assist people in finding a suitable donor from a pool of 230,000 "typed" volunteers ready and willing to donate their life-giving marrow; and

WHEREAS there is an urgent, nationwide need to increase the pool to 1,000,000 available marrow donors of all ethnic backgrounds to increase the chance of finding a suitable donor for the 10,000 people who are currently awaiting a bone marrow transplant throughout the United States and who will die without a bone marrow transplant; and

WHEREAS thousands of people have already died for lack of a suitable marrow donor and this same grim prospect faces many other patients and their families throughout Alaska; and

WHEREAS it is necessary to promote a greater awareness of the need for healthy bone marrow donors and to encourage Alaskans to step forward to be typed and enrolled into the National Bone Marrow Donor Registry so that the pool of donors is as large and diverse as possible; and

WHEREAS Senate Bill 177 and Senate Concurrent Resolution 17 and House Bill 211 and House Concurrent Resolution 16 will designate April 14-20, 1991 as "Bone Marrow Donor Week" and will provide funds for public education, recruitment and blood-testing of 3000 Alaskan bone marrow donors;

BE IT RESOLVED that the Alaska School Nurses Association strongly encourages passage of Bone Marrow Donor Program legislation; and be it

FURTHER RESOLVED that copies of this resolution be sent to Governor Wally Hickel; Commissioner of Health and Social Services Ted Mala; all Senators and Representatives of the State of Alaska Seventeenth Legislature; and to all School Nurses in the State of Alaska.

Passed April 12, 1991
Alaska School Nurses Association

Alaska State Legislature

SENATOR
ARLISS STURGULEWSKI

Senate

3111 C STREET, SUITE 550
ANCHORAGE, ALASKA 99503
(907) 561-7615

While in Juneau
P.O. BOX V
JUNEAU, ALASKA 99811
(907) 465-3818

March 13, 1991

Adella Johnston
9901 Toakee Circle
Eagle River, Alaska 99577

Dear Adella:

Thank you for your message in support of SB 177 relating to an appropriation to the Department of Health and Social Services for payment as a grant to Blood Bank of Alaska, Inc. This grant will assist the Blood Bank in increasing the enrollment of Alaskans as bone marrow donors in the national bone marrow donor registry.

This bill was heard yesterday in the Senate Health, Education and Social Services Committee, which I chair. I am pleased to report that the bill passed out of committee with my support and has moved on to the Senate Finance Committee. I would encourage you to contact the members of that committee and let them know of your support for SB 177. Senators Kerttula and Pourchot are co-chairs of Senate Finance and members are Senators Duncan, Adams, Hoffman, Shultz, and Uehling.

Again, thank you for contacting me regarding SB 177.

Kindest regards,

Arliss Sturgulewski
Alaska State Senator

PUBLIC OPINION MESSAGE

DEAR: SENATOR STURGULEWSKI

NAME: ADELLA JOHNSTON
TITLE:
ADDRESS: 9901 TOAKEE CIRCLE
CITY: EAGLE RIVER ZIP: 99577
PHONE: 696-3929
BILL NO: SB 177
SUBJECT: APPROP: BLOOD BANK OF ALASKA, INC.
MESSAGE: PLEASE SUPPORT AND PASS SB 177 BECAUSE EVERY YEAR 22 ALASKANS NEED A BONE MARROW TRANSPLANT. THIS BILL WOULD PROVIDE FUNDS FOR THE BLOOD BANK OF ALASKA TO TISSUE TYPE POTENTIAL DONORS. WITHOUT THIS DONATION OF BONE MARROW, RECIPIENTS WOULD ALMOST CERTAINLY DIE. THIS TISSUE TYPING IS NECESSARY BECAUSE YOU ARE AT AN APPROXIMATE 1 IN 20,000 TO MATCH. /BN

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UEHLING

TO: Members of Senate Health, Education, and Social Services

RE: Senate Concurrect Resolution No. 17 ✓

Although I'm not able to attend this teleconference in person, I wanted to express my support for Senate Resolution No. 17, designating April 14th-20th as Bone Marrow Donor Week.

As a nurse working with children who had cancer, I saw the anguish families go through in looking for a treatment to save their child's life. For some children and adults with certain types of cancer or blood disorders, the only known successful treatment is bone marrow transplant.

I also know there are people willing to donate bone marrow if they were a match, in order to help in someone's fight for survival. But we need to raise the awareness level and numbers of people willing to have their blood typed for possible bone marrow donation. Increasing the number of people in the National Bone Marrow Registry would help save Alaskans, as well as others across the nation.

Please show your support in this endeavor, by passage of Resolution No. 17, as well as funding measures to help in the blood typing costs.

Respectfully,

Margaret Volz, R. N.

Houston Jr Sr High
Box 521060
Big Lake 99652
892-9250

FAX TRANSMITTAL MEMO

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VALLEY

Kathleen A. Walker
Director, Community Relations

315 E. Dahlia
P.O. Box 1687
Palmer, AK 99645

907-745-4813 X 208
FAX 745-4850

March 11, 1991

FROM: Kathleen Walker, Director Community Relations, Valley Hospital, Palmer, Alaska

TO: Senators Sturgulewski, Fischer, Cotton, Hoffman and Menard

SUBJECT: Senate Bill Number 177 and Senate Concurrent Resolution Number 17

I am pleased to have the opportunity to present testimony for this bill and resolution for a number of reasons; personal as well as professional

Valley Hospital understands the far reaching effect this program could have in saving lives through bone marrow transfusions for certain cancer patients.

We know there are already a number of Mat-Su Valley residents anxious to become listed on the National Bone Marrow registry.

The Blood Bank of Alaska is to be commended for their immediate and complete support in helping to get this program started in Alaska, along with the impetus provided by Eileen Albert, an Alaskan resident in immediate need of a bone marrow transplant.

This is a relatively new program, just established in 1987, which gives new hope to patients and their families. As new people enter the program each day as possible donors, chances for the survival of patients with certain types of cancer is increased. On a more personal note, I am the mother of a child who died of cancer in 1986, at the age of 2 1/2. Although my son died of complications following surgery for his cancer, a bone marrow transplant would have been our next step. No match had been located at that time. During the course of our stay in Seattle at Children's Hospital, we came to know a number of children who might be alive today if such a program had been in place then. The development of this program is very dear to my heart.

Senate Bill 177, under consideration by your committee today, provides for a grant in the amount of $222,000 to be used by the Blood Bank of Alaska to help pay for the costs associated with increasing the enrollment in the Bone Marrow Donor registry. It is extremely important that all eligible donors be given the chance to participate in this program, whether or not they can afford to pay the test processing fee. This bill would help make increased enrollment a reality.

COMREL.021

Valley Hospital has already made a commitment to assist with the Bone Marrow Donor drive in the Mat-Su Valley.

We strongly urge you to pass Senate Bill 177 and to encourage the enrollment of donors in this program with your unanimous support.

Kathleen Walker

Kathleen A. Walker
Director, Community Relations
Valley Hospital Association, Inc.
Palmer, Alaska

Citizens of Alaska present at the testimony given before the Senate HESS Committee in Support of Senate Bill 177 and Senate Concurrent Resoultion 17.

March 12, 1991

Legislative Information Office
3111 C Street
Anchorage, Alaska

Dolores Weiler
Volunteer Support for the Marrow Donor Program
Chair, Board of Directors
Blood Bank of Alaska, Inc.

Peggy Burgin
Volunteer Support for the Marrow Donor Program
Member at Large, Board of Directors
Blood Bank of Alaska, Inc.

Rhonda Fehlen
Volunteer Support for the Marrow Donor Program
Member, Board of Directors
Blood Bank of Alaska, Inc.

Vicki Turner
Volunteer Support for Marrow Donor Program
Member, Board of Directors
Blood Bank of Alaska, Inc.

V. Gaye Hurley
Registered Bone Marrow Donor
Volunteer Support for the Marrow Donor Program
Executive Director, Blood Bank of Alaska, Inc.

Frank E. Baker
Public Affairs
BP Exploration (Alaska) Inc.
Corporate sponsor for BP employee Marrow Donor Drive

Kathleen Walker
Director of Public Relations
Valley Hospital
Volunteer Coordinator For the Marrow Donor Program in the Matanuska-Susitna Valley

Katheryn Cersosimo
Volunteer Support assisting in recruitment of donors for the Marrow Donor Program

Doris Moody
Donor, Marrow Donor Program
(First Alaskan donor from the Blood Bank of Alaska's Marrow Donor Program to successfully match an unrelated patient)

Margaret Volze
Volunteer Coordinator for the Marrow Donor Program
School Nurse, Houston Alaska
(first unrelated Marrow Donor for the State of Minnisota)

Life Search

Volume 2, Number 1

A Newsletter of the National Marrow Donor Program

April, 1990

ABOVE: In February, unrelated marrow recipients Rae Lynn and Christian were invited, along with their mothers, to the White House to tape a Public Service Announcement (PSA) about the need for more marrow donors. Mrs. Bush was a hit with the kids and the kids were a hit with the press. Many donated their services to make the special effort possible (see p. 4). The PSA and accompanying flyer are now available through the NMDP Office.

100,000 and Still Climbing!

Since Thanksgiving, the National Marrow Donor Program (NMDP) has seen phenomenal growth. The success is due to "determined Moms and Dads," corporate and political leaders willing to help blaze a new path and, especially, tens of thousands of Americans who have become NMDP volunteers.

Led by NMDP's community recruitment group, LIFE-SAVERS Foundation of America, great strides have been made in climbing to the U.S. goal of 250,000 volunteer donors. The new NMDP worldwide goal is one million volunteers willing to be the stranger who offers the living gift of life to a patient with leukemia or other fatal blood disease.

Many NMDP Donor Centers have also experienced increases in platelet and blood donations and thousands of other Americans have opened their pocketbooks to sponsor a volunteer's typing test.

Much still remains to be done. NMDP participants continue to struggle with raising the necessary funds for the HLA typing test of volunteer donors. Great strides have been made in minority recruitment but these efforts must continue.

Most importantly and tragically, many patients still die while they wait with their families for the miracle match which cannot be found without a larger volunteer NMDP Registry.

RIGHT: In January, the NMDP Asian Donor Recruitment Program held a successful "Casino Night" to raise funds for typing tests. "The first step is education..to break old traditions," said Jonathan Leong, the new President of the Asian Project.

Coordinating Center · 100 South Robert Street ◆ St. Paul, Minnesota 55107 ◆ 1-800-654-1247

Chairman's Privilege

Bud Zumwalt

Since last writing to you, great strides have been made in every facet of our Program. A train called momentum, powered by a generous human spirit, has rarely slowed in the past four months.

As directors of this Program, it has been a great challenge to ensure that we respond to the many needs of such a rapidly expanding Program. While phone lines have been overloaded, brochures have had to be reprinted, temporary help has been needed by donor centers and our Board's Executive Committee can't seem to go a day without a conference call, we've been phenomenally successful:

- Approximately 25 miracle matches are now made each month, offering the chance of a cure to those with leukemia or other blood disease. Three years ago, without the NMDP, only 25 unrelated matches were made each year. I hope that one day soon we will be finding that miracle match for 25 people per day.

- This month, we will top 100,000 volunteers on our U.S. Registry.

- International expansion and dialogue continues. It has been stunning to see the political and cultural barriers dissolve as we discuss this wonderful Program and the need for cooperation.

- While a desperate need for minority volunteers remains, we can be proud of our progress in the last few months. Certainly, we remain committed to aggressively continuing these special recruitment efforts.

- After much negotiation and discussion, we are nearing the end for our journey in establishing NMDP as a free-standing organization. Many dedicated individuals, including Dr. Claude Lenfant, Director of the National, Heart, Lung and Blood Institute, have assisted as we've blazed this path of bringing NMDP to maturity.

- Our network of donor, transplant and collection centers continues to expand.

- Efforts at public education have become broader with the help of the First Lady, many competent reporters and others helping us shape responsible yet concise information about becoming a donor.

- We have initiated some exciting new research projects and are in the process of readying our cell line repository for study by the International Histocompatibility Workshop.

I commend each and every participant in this Program for exhibiting flexibility, perseverance and most of all, compassion. The path we have blazed is one which should inspire us all to believe that great challenges can be met when the human spirit is involved.

National Marrow Donor Program

Coordinating Center
100 S. Robert St.
St. Paul, MN 55107
1-800/526-7809

Board Chairman:
Adm. E. R. Zumwalt, Jr.
Vice Chairman:
Robert C. Graves, DVM.
Secretary:
John A. Hansen, M.D.
Treasurer:
Herbert A. Perkins, M.D.
Executive Director:
Douglas A. Shaw
Editor:
Elisabeth A. Quam

A collaborative effort of the American Association of Blood Banks; American Red Cross; and Council of Community BloodCenters.
With funding from the National Heart, Lung, and Blood Institute

The Blood Center of Southeastern Wisconsin (Milwaukee) reached a major milestone in February when it provided its 100th unrelated marrow donor. "While we are extremely proud to have reached this milestone, 100 doesn't even begin to represent the number of people in our registry who would love to help others, should the opportunity arise," said Gayle Bass, supervisor of The Blood Center's Bone Marrow Donor Program. She is pictured at right with 100th donor, Nancy.

Connecticut, New York on Minnesota's Heels

Model Legislation Considered by Many States

On February 6, Minnesota had a Capitol donor day. The first two NMDP volunteers were Public Safety Commissioner Paul Tschida and Sen. Dennis Frederickson (in the background)

Connecticut Speaker of the House, Richard Balducci, became a NMDP volunteer on March 15 during a special blood drive of the Hartford ARC. The Connecticut Legislature has held hearings on donor recruitment. (Photo by Mark McGrath, courtesy of The Newtown Bee.)

What the State Model Legislation Proposes:

1. The Commisioner of Health is instructed to assist in educating state residents, with special emphasis on minority populations ($15,000-20,000).

2. A marrow donor drive will be conducted among state employees with the state picking up the cost of the first 200 tests as an example to private employers ($15,000).

3. Individuals who are the miracle match for a patient are assured time off from work.

4. Employers are allowed a business deduction for employee recruitment and typing expenses.

State Effort Supplements National Crusade

From all over the country, state officials have contacted the NMDP office to ask how they can help in the continuing crusade to offer hope and help to the thousands of patients in need of a stranger's gift.

While many of NMDP's challenges must be confronted on a national and international level, help at the state level can provide needed education and impetus to the private sector. With the help of Minnesota Rep. Charlie Weaver, model legislation was developed and through the work of the St. Paul ARC, related activities were planned and implemented.

Many individuals assisted Minnesota's donor center in this capacity, including Opperman Heins & Paquin which contributed some of the funds to type state legislators.

Connecticut's Gov. O'Neill declared March as Bone Marrow Donor Registration Month and New York's State Sen. Eugene Levy has organized a similar week in New York on May 14-18.

Key components of the Minnesota week, which are being followed by other states include:

- Marrow Donor Week/Month with related media and donor recruitment activities;
- Hearings on versions of the Model Legislation;
- Capital Education Day and donor sign up for legislators and staff; and
- Private Sector Employee Recruitment Drives.

To request a packet of information regarding the model legislation, call the NMDP. Ask for Liz Quam if you have questions about progress in various states.

Minnesota State Rep. Charles Weaver (l) and Sen. Gene Merriam (r), witness as Gov. Rudy Perpich declares Marrow Donor Week in Minnesota. Standing left to right: RoxAnn Strand, RN and David Therkelsen (St. Paul ARC); Chris Berne (corporate response participant, Berne Scale Co.); David Stroncek, M.D. (St. Paul ARC); George Kohler (LifeReach); Betty Lynch (ARC Midwestern Hdqtrs); Robert Jursnick (St. Paul ARC); Randy Weddle (ARC Midwestern Hdqtrs); and Liz Quam (NMDP).

Bulletin Board

- NMDP is compiling a list of corporations who have responded to requests for help. Please forward names of companies, big and small, to Linda Abress at NMDP. Dow, Tandem Computers, Union Pacific Resources, General Mills and McDonnell Douglas are some of the companies who have already responded.

- Congressional interest in NMDP continues. Have you written your congressman to express your appreciation for the Program? NMDP Vice Chairman Robert Graves testified before the Senate Labor and Human Resources Committee in March. For a copy of his testimony, send a self-addressed large envelope to the NMDP.

- Know someone who should be on the newsletter mailing list? Please send names in writing to the NMDP.

- CALL AGAIN! With NMDP's help, LIFE-SAVERS has a new phone system. Encourage individuals to call 1-800-950-1050 or 1-900-990-1414. The 900 number will cost the caller $5.00 which is applied to the enormous materials and postage bill LIFE-SAVERS has each month.

- International cooperation and expansion continues. In January, NMDP, England, France, Canada, The Netherlands and Australia set up an administrative group to review and develop standards for international operations.

Special Thanks to: Xoma Corporation, Candace Peterson, Cal Covert, Scott Long, Toni Cudney, Martha Covert, Kelly Cusick, Fuller Productions, R&S Litho, Gordon Robinson and Associates and Robert Pittenger for helping NMDP's PSA become a reality. Time, talent and services were donated for the effort. Special, special thanks to Rae Lynn and Christian and their families.

Charlotte, NC has been a hot spot for donor recruitment. Those involved saw first hand the hope and help available when local recipient Donnie (l) and his local donor Ray finally met. Said Donor Coordinator Kay Piercy of the event, "Today is the result of over a year of highs and lows — it's the pay-off — the reason we all have for riding the emotional roller coaster together and finally arriving at our destination with joy in our hearts."

Recent Scientific Articles of Note:
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- Beatty, P.G., Atcher, C., Hess, E., Meyer, D.M., Slichter, S.J., Recruiting blood donors into a local bone marrow donor registry. *Transfusion* 29:778-782, 1989.
- Gingrich, R.D., Ginder, G.D., Goeker, N.E., Howe, C.W., Wen, B.C., Hussey, D.H., Fyfe, M.A., Allogeneic marrow grafting with partially mismatched, unrelated marrow donors. *Blood* 5:1375-1381, 1989.
- Thomas, E.D., Clift, R.A., Indications for marrow transplantation in chronic myelogenous leukemia, *Blood* 73:861-864, 1989.
- Sullivan, K.M., Witherspoon, R.P., Storb, R., Buckner, C.D., Sanders, J., Thomas, E.D., Long-term results of allogeneic bone marrow transplantation, *Transplant.Proc.* 21:2926-2928, 1989.
- Beatty, P.G., Hansen, J.A., Anasetti, C., Sanders, J., Buckner, C.D., Storb, R., Thomas, E.D., Marrow transplantation from unrelated HLA-matched volunteer donors, *Transplant. Proc.* 21:2993-2994, 1989.

Staff Profile: Pat Coppo, Director of Program Services

Patricia Coppo is a familiar NMDP face who's taken on added responsibilities at the Coordinating Center. As the new Director of Program Services, Pat oversees NMDP research activities.

As the staff aide to the Research and Publications; Histocompatibility; Standards; and Donor and Patient Safety Monitoring Committees, Pat's responsibilities are varied. While assisting in the development and implementation of research studies and monitoring the collection of data, Pat also must assist in assuring the quality of NMDP's HLA typing and donor registry and the monitoring of the quality and completeness of the the very important NMDP cell and serum repository.

"I love my job," said Pat. "I know how important research is to marrow transplantation therapy and to the NMDP. I'm happy I can be a part of something so significant."

Kicks-Off "Prototype" Recruitment Effort:

Congressman Bill Young Asks for Help at Home

Congressman Young announced the Pinellas County drive at a press conference at All Children's Hospital in St. Petersburg, FL on March 9. He's flanked by Dr. Robert Good and Admiral Zumalt, both of the NMDP Board. The Congressman was an integral part of creating the national registry and continues his advocacy for the Program in Washington, D. C., and now in his home district as well. At right is the Congressman with Jolene, one of the local patients waiting for a miracle match.

Starting with a newsletter to all his constituents in Pinellas County (St. Petersburg, FL), Congressman Young announced in March that he would lead a drive to add more volunteers to the NMDP Registry. "Our goal is to add 5,000 Pinellas County volunteers to the registry. Officials of the NMDP plan to use our drive as a model program to recruit donors throughout our nation," said Young.

Herbert A. Perkins, M.D.

"A Kind Man, A Good Scientist" Describes NMDP Treasurer

According to many observers, one of the great strengths of the NMDP is its prestigious Board of Directors.

Herbert A. Perkins, M.D., Treasurer and Co-Principal Investigator of the NMDP, is a Board member who is highly respected for his medical knowledge and his vision for both the NMDP and the American Association of Blood Banks.

"Dr. Perkins is obviously well-known in the field of transfusion medicine," said Charles Wallas, M.D., another member of the Board. "He's recognized as an individual who has contributed to the field and is a great asset to the NMDP.

"He's highly regarded...I think the world of Herb. He's a kind man and a good scientist," Wallas added.

Perkins, a cum laude Harvard graduate and a summa cum laude graduate of the Tufts University School of Medicine, is also the Executive, Medical and Scientific Director of the Irwin Memorial Blood Center (IM) in San Francisco. It is at IM that the NMDP maintains its Cell Repository, a bank of blood samples from all NMDP donors and recipients. Medical researchers from around the world can make application to study these pairs of samples.

The "very early days" was how Perkins described his involvement with unrelated marrow donor issues. In the late 1970's, Perkins was already participating in discussions about the possibility of a large registry of volunteers willing to offer the living gift of life to a stranger.

"I've remained involved because of the importance of the services and opportunities offered by the NMDP. I want to help keep [the NMDP] moving," said Perkins.

As treasurer of the the organization, Perkins serves as chair of the NMDP Finance Committee. He also heads the Standards Committee which addresses medical protocol for both donors and recipients. "Donor Protection" remains an important mission of the NMDP, according to Perkins.

Along with his duties at IM, Perkins is a Research Associate at the Cancer Research Institute and a Clinical Professor of Medicine at the University of California School of Medicine, San Francisco.

Perkins said his hopes for the NMDP "remain high but we have to be ready to take advantage of opportunities, to be prepared to switch directions as we build and maintain a system that is responsive to both recipients and donors."