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REPRESENTATIVE BETTY BRUCKMAN

House Bill No. 378

"An Act requiring certain employers to grant employees leave for medical purposes connected with the donation of bone marrow"

SPONSOR STATEMENT

I have introduced HB 378 to insure that every matched Alaskan donor is able to give the "gift of life" by requiring certain employers to grant paid leaves of absence to an employee who has been identified as a match by the National Marrow Donor Program. Oregon and Minnesota have already enacted comprehensive legislation that authorizes donor recruitment drives for state employees and requires certain businesses to guarantee employees time off in order to donate marrow.

The Bone Marrow Donor Program of Alaska, thanks to the efforts of this Legislature, has been able to successfully match six Alaskan donors with patients suffering from cancer or other fatal blood disorders. The statistics for marrow compatibility range from one in one hundred to one in one million for Caucasians and matches for Alaskan Natives and other minority populations are unfortunately much, much higher, due in part to the lack of registered donors, a crisis that is being remedied in part by the Alaska Blood Banks donor drives in rural Alaska. As a direct result of the special appropriation passed last



year, an additional 2200 potential donors have been typed and enrolled in the National Marrow Donor Program . There is still much that needs to be done to ensure that compatible donors are found for the estimated 1400 active searches being conducted nationally on any given day. This legislation is a positive step toward finding a miracle match for everyone who needs one.

Enclosed in your packet is an article about Ina Kristianson, a constituent who has just this week entered the UCLA Medical Center to receive her marrow transplant and late last year a 7 year old Fairbanks girl received her marrow transplant and is progressing well. There are still a number of Alaskans waiting for compatible donors, including Eileen Albert of Eagle River. Donor drives are currently scheduled for Kodiak and Dutch Harbor and I am very pleased to report that the Blood Bank has been able to reduce the logistical and administrative overhead costs of the Donor Grant Program and will be seeking a grant adjustment allowing them to shift grant dollars from overhead to direct services (tissue typing).

FISCAL NOTE

STATE OF ALASKA
1992 LEGISLATIVE SESSION

BILL NO. HB 378

Revision Date: _____
Title: Requiring certain employers to grant leave for bone marrow donations
Sponsor: Bruckman
Requestor: _____

Department Affected: Administration
BRU: Personnel
Component: Personnel

COMPONENT SERIAL NO.

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Expenditures/Revenues: (Thousands of Dollars)

OPERATING	FY 93	FY 94	FY 95	FY 96	FY 97	FY 98
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
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REVENUE FUND SOURCE:	0	0	0	0	0	0
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FUNDING: (Thousands of Dollars)

GENERAL FUND	0	0	0	0	0	0
FEDERAL FUNDS	0	0	0	0	0	0
OTHER FUND SOURCE:	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: \$0

ANALYSIS: (Attach a separate page if necessary.)

A small, but undetermined number of State employees can be expected to undergo procedures to donate bone marrow in any year. However, the total number and total time off with pay will be so small, even at a component level, that no additional appropriation will be required.

Prepared by: R. H. King, Director
Division: Personnel

Phone: 465-4430
Date: _____

Approved by Commissioner: Nancy Bear Usery
Agency: Administration

Date: 1-17-92

Distribution (by preparer): Leg. Fin., Legislative Sponsor, Requestor, OMB/DBR, Gov. Legis. Ofc., & Impacted Agency(ies).



SUMMARY OF KNOWN STATE ACTIVITIES
PROMOTING PUBLIC AWARENESS AND RECRUITMENT OF
MARROW DONOR VOLUNTEERS

July 15, 1991

ALASKA

Passed Senate Bill No. 177 (1991) which gave the Blood Bank of Alaska, Inc. \$222,000 to help it increase the enrollment of Alaskans as marrow donor volunteers in the national bone marrow donor registry.

Alaska also passed Senate Resolution No. 17 (1991) which designated April 14-20, 1991 as "Bone Marrow Donor Week."

CALIFORNIA

Created Chapter 889 (1990) of the Health and Safety code which required the office of statewide Health and Planning and Development to promote the awareness of the need for potential bone marrow donors from the ethnic minority communities. It also allocated the sum of \$145,000 to help fund this project.

Among other pending legislation, two bills are currently being reviewed in the California legislature:

A) Assembly Bill No. 2209 (1991) would establish rules in the California Health and Safety Code which would regulate organ and tissue transplant centers.

B) Assembly Bill No. 136 (1991) which would establish an office of Minority Health Affairs which would, among other responsibilities, help to increase the awareness of the need for potential marrow donors within minority groups.

COLORADO

Passed House Bill No. 1055 (1989) which encouraged donations of anatomical gifts for transplants. In order to do this it made a rule providing two days of paid leave per year for employees in the state personnel system for the purpose of donating organs, tissue or bone marrow for a transplant.

CONNECTICUT

Passed Substitute Senate Bill No. 112 (1988) which allocated \$25,000 to The Department of Health Services to study the feasibility of a pilot program for a bone marrow registry in the Stamford Health Department.

In 1990, the Connecticut legislature considered bill No. 5947 which would have allocated \$50,000 to the Department of Health Services. This bill died in the appropriations committee.

In 1991, the Governor designated the month of April 1991 as "Bone Marrow Donor Registration Month" in Connecticut. During this month, a blood and marrow testing drive was held for legislators and others in the capitol, using some of the \$115,500 which was allocated from the state for this purpose.

FLORIDA

Passed House Bill 1027 (1991), which allocated \$25,000 to type marrow donor volunteers in Florida for the National Marrow Donor Program.

GEORGIA

Passed House resolution 492 (1991) which encouraged the citizens of Georgia to donate their tissues and body organs.

HAWAII

Allocated \$50,000 in 1989 for tissue typing. Further funding legislation is pending.

The governor proclaimed one week in 1990 as "Bone Marrow Awareness Week."

MAINE

Passed Legislative Document 1719 (1991) which initiated and funded a bone marrow donor education program (\$40,000) and a bone marrow donor drive (\$20,000 for typing of state employees). The bill also protects the jobs of employees who need time off in order to donate marrow.

MARYLAND

Senate Bill 446 (1991) died in the finance committee. The bill would have expanded the duties of the Organ Donation and Transplantation "clearinghouse" established in 1990.

WEST VIRGINIA

Introduced Senate Bill 17 (1991). This bill was similar to the one that was passed in Minnesota in that it would have established a State Bone Marrow Donor Program, including a donor education program, job protection for donors, and a drive for state employees. This bill died in committee.

MASSACHUSETTS

Introduced House Bill No. 5058 (1990) which would have established a bone marrow donor program in the department of public health. This program would encourage the recruitment programs for prospective donors of bone marrow, to maintain lists of volunteers for marrow transplants, seek funds and facilities for blood tests for prospective donors, establish and maintain (in cooperation with the National Marrow Donor Program) a registry and data bank of persons who need a marrow transplant and prospective compatible donors for the harvesting of said marrow. This bill did not pass.

House Bill No. 5106 (1990) is pending which would establish a bone marrow donor fund from certain revenues received from voluntary contributions through state income tax forms which would be used to type potential bone marrow donors.

MINNESOTA

Passed S.F. 1093 (1991) which established and funded a Bone Marrow Donor Education Program (\$40,000) through the Department of Health and a bone marrow donor drive (\$15,000 for the typing of state employees). The bill also mandates employers give employees time off in order to donate marrow (up to 40 hours of paid leave).

The governor signed a proclamation declaring the week of March 4-10, 1990, to be "Bone Marrow Donor Week."

NEW JERSEY

Passed Assembly Resolution 3101 (1990), which required insurers to pay for bone marrow transplants in the treatment of certain types of cancer.

Is considering Senate Resolution 2811 (1991), which would provide for a checkoff on state income tax returns to permit taxpayers to contribute a portion of their refund to a "Bone Marrow Donor Typing Fund."

Is considering Assembly Joint Resolution 86 (1991), which would designate a "Bone Marrow Donor Week."

NEW YORK

A packet of bills was introduced into the New York State Senate and the State Assembly (1991). The package:

- A) Implements a bone marrow donor education and gift program.

B) Requires certain health insurance policies to cover bone marrow transplants.

C) Requires employers to grant a paid leave of absence (not to exceed 40 work hours) to employees for the purpose of donating their marrow.

D) Provides for tax credits for employers who sponsor marrow tissue typing programs.

Passed a legislative Resolution (Senate No. 1087 and Assembly No. 1056) in 1991 which designated May 13-17, 1991 as Bone Marrow Donor Awareness Week in New York State.

OREGON

Passed Senate Bill 813 (1991) which establishes a bone marrow transplant program in the state of Oregon. The bone marrow transplant program will:

A) Educate the residents of Oregon about the need for bone marrow donors; the procedures required to become registered as a potential bone marrow donor; and the medical procedures required for the actual removal of bone marrow.

B) Make special efforts to educate and recruit minorities as potential donors.

C) Guarantee any employee up to 40 hours of paid leave for the purpose of donating bone marrow.

D) Endorse a marrow testing drive for any state employees, the funds for which will be collected by tax deductible donations to the National Marrow Donor Program through the state of Oregon Employee Bone Marrow Drive Account.

E) Authorize a business tax credit which will be 25% of the cost incurred by the business because of bone marrow typing or donation by its employees.

TEXAS

Introduced Senate Bill 84 (1991) which encouraged the HLA tissue typing of the state's employees. It would have paid the laboratory fees for the state employees, and would have guaranteed the paid leave of absence for these employees if they were determined to be a match. This bill did not pass.

House Concurrent Resolution No. 11 (1991) was signed by the Governor which designated April 20, 1991 as "Because I Care Bone Marrow Awareness Day."

Presented to the governor April 24, 1990

Signed by the governor April 26, 1990, 10:51 p.m.

CHAPTER 536—S.F.No. 1903

An act relating to health; providing programs and incentives for persons to volunteer as bone marrow donors; requiring the commissioner of health to educate residents about the need for volunteer bone marrow donors; requiring paid leave for employees to donate bone marrow; requiring a bone marrow donor drive to encourage state employees to volunteer as bone marrow donors; appropriating money; proposing coding for new law in Minnesota Statutes, chapters 145 and 181.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

Section 1. [145.927] BONE MARROW DONOR EDUCATION.

The commissioner of health shall educate residents of the state about:

- (1) the need for bone marrow donors;
- (2) the procedures required to become registered as a potential bone marrow donor, including the procedures for determining the person's tissue type; and
- (3) the medical procedures a donor must undergo to donate bone marrow and the attendant risks of the procedure.

The commissioner shall make special efforts to educate and recruit minority populations to volunteer as potential bone marrow donors. Means of communication may include use of press, radio, and television, and placement of educational materials in appropriate health care facilities, blood banks, and state and local agencies. The commissioner of health, in conjunction with the commissioner of public safety, shall make educational materials available at all places where drivers' licenses are issued or renewed.

Sec. 2. [181.945] LEAVE FOR BONE MARROW DONATIONS.

Subdivision 1. DEFINITIONS. (a) For the purposes of this section, the following terms have the meanings given to them in this subdivision.

(b) "Employee" means a person who performs services for hire for an employer, for an average of 20 or more hours per week, and includes all individuals employed at any site owned or operated by an employer. Employee does not include an independent contractor.

(c) "Employer" means a person or entity that employs 20 or more employees at at least one site and includes an individual, corporation, partnership, association, nonprofit organization, group of persons, state, county, town, city, school district, or other governmental subdivision.

New language is indicated by underline, deletions by strikethrough.

Subd. 2. LEAVE. An employer must grant paid leaves of absence to an employee who seeks to undergo a medical procedure to donate bone marrow. The combined length of the leaves shall be determined by the employee, but may not exceed 40 work hours, unless agreed to by the employer. The employer may require verification by a physician of the purpose and length of each leave requested by the employee to donate bone marrow. If there is a medical determination that the employee does not qualify as a bone marrow donor, the paid leave of absence granted to the employee prior to that medical determination is not forfeited.

Subd. 3. NO EMPLOYER SANCTIONS. An employer shall not retaliate against an employee for requesting or obtaining a leave of absence as provided by this section.

Subd. 4. RELATIONSHIP TO OTHER LEAVE. This section does not prevent an employer from providing leave for bone marrow donations in addition to leave allowed under this section. This section does not affect an employee's rights with respect to any other employment benefit.

Sec. 3. BONE MARROW DONOR DRIVE.

The commissioner of health shall conduct a bone marrow donor drive to encourage state employees to volunteer to be potential bone marrow donors. The drive shall include educational materials and presentations that explain the need for bone marrow donors, and the procedures for becoming registered as potential bone marrow donor. The commissioner of employee relations shall provide assistance as needed to organize and conduct the drive. The bone marrow donor drive must be completed by June 30, 1991.

Sec. 4. APPROPRIATIONS.

Subdivision 1. BONE MARROW DONOR EDUCATION. \$40,000 appropriated from the general fund to the commissioner of health for the bone marrow donor education required in section 1. The funds are available until June 30, 1991.

Subd. 2. BONE MARROW DONOR DRIVE. \$15,000 is appropriated from the general fund to the commissioner of employee relations to pay the costs of typing the tissue of the first 200 state employees who are recruited under the bone marrow drive in section 3 to be potential bone marrow donors. The funds are available until June 30, 1991.

Presented to the governor April 24, 1990

Signed by the governor April 26, 1990, 9:30 p.m.

New language is indicated by underline, deletions by strikethrough.

By registering
as a marrow donor,
you could save
a stranger's life.

Marrow transplants are not possible for many people because there are not enough volunteer donors available.

There is a special need for donors of African, Asian, Hispanic and Native American descent. Although fatal blood diseases strike people of all races, more than 85% of the registered volunteer donors are Caucasian.

Hundreds, perhaps thousands, of lives could be saved if more people signed up — people like you.

What is the benefit
to you as a donor?

"The benefit of giving marrow to this child and any other child or any other person, is that you get the gratitude in your heart of knowing that you have actually saved someone's life."

Mrs. Sheila Holladay,
mother of David,
a two-year-old with leukemia

Barbara Bush with children who were saved through bone marrow transplants.



Minnesota Department of Health
Minnesota Marrow Donor Program
717 S.E. Delaware Street
Box 9441
Minneapolis, MN 55440
National Marrow Donor Program
(800) 654-1247

Participating Organizations:

St. Paul Area Red Cross
Memorial Blood Center of
Minneapolis
National Marrow Donor Program

Someone
just like you
saved
Kellie's life.



You could save
a person's life...



Recycled Paper

For two-year-old Kellie Shallert, a stranger was her only hope.

Doctors said Kellie had Combined Immune Deficiency Syndrome – a condition in which the immune system does not work properly. Without a bone marrow transplant, Kellie could die.

Her parents and brother were tested as possible marrow donors, but none of them matched her marrow type. Fortunately, the National Marrow Donor Program found a volunteer donor who did match. Today, thanks to that gift from a stranger, Kellie is doing fine.

Like Kellie, nearly 70 percent of the people with leukemia or other fatal blood diseases do not have a match within their families. These people need to find donors who aren't related to them – people willing to help someone they may never meet.

Many donors are needed.

Patients have between a 1-in-100 and 1-in-1,000,000 chance of matching an unrelated donor, so a large number of potential donors is needed. Even though most people who sign up to be donors will probably not be called to give marrow, just being registered increases the odds of finding a miracle match.

What does it take to become a donor?

- Marrow donors must be between the ages of 18 and 55 and be in good health.
- A simple blood test is done to identify the volunteer donor's Human Leukocyte Antigen (HLA) tissue type.
- The volunteer's tissue type is confidentially entered into the National Marrow Donor Program computer.
- If the volunteer is matched to a patient, the volunteer is given detailed information about the procedure.
- If the volunteer agrees to participate, about 5 percent of his or her marrow is removed in a simple surgical procedure. It takes the adult body about two weeks to replace the marrow.
- After the procedure, an overnight hospital stay is usually required. The donor can expect to feel some soreness for a week or two.

In Minnesota, employees who sign up to become donors are eligible for up to 40 hours of paid leave from their jobs for marrow testing and donation.

Please help now. Register to be a marrow donor.

For more information about how you can become a donor, complete this form and mail it to:

Minnesota Department of Health
Minnesota Marrow Donor Program
717 S.E. Delaware Street
Box 9441
Minneapolis, MN 55440

or call:

the National Marrow Donor Program
1-(800) 654-1247

Name

Address

City

County

State

Zip

Work Phone

Home Phone

Date of Birth

Check this box if you are interested in helping to promote marrow donation in your community.



BACKGROUND ON THE NATIONAL MARROW DONOR PROGRAM

■ Marrow transplantation, from unrelated donors, is a relatively new and viable medical therapy for patients with fatal blood diseases such as leukemia and aplastic anemia. While the National Marrow Donor Program (NMDP) now has almost 500,000 volunteer donors on its Registry, it is still only finding matches which result in transplant for 30% of the patients who search the Registry. NMDP still needs:

1. More volunteers (especially non-Caucasians) willing to give the living gift of life;
2. More funds to pay for the HLA typing test which identifies the antigens which must be matched; and
3. More time to build an international registry (many developed countries are just beginning to set up their national registries).

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

■ The NMDP Coordinating Center is located in Minneapolis, MN. The NMDP Registry is one of the most sophisticated biometric programs in the world. NMDP has a contractual relationship with the federal government, through the National Heart, Lung, and Blood Institute, to run a national registry.

■ NMDP has only been in existence since 1987 (more than 1000 transplants between 12/15/87 and 12/15/91) and has experienced rapid growth. This has been made possible because of the generosity of hundreds of thousands of Americans willing to be the stranger who offers the living gift of life. NMDP now is facilitating about 40 transplants a month. Admiral Zumwalt, NMDP Chairman of the Board, has stated that the goal is 25 transplants a day.

■ NMDP volunteers have offered two tablespoons of their blood for HLA or tissue typing and have signed a consent to have the typing tests results entered on the NMDP Registry, which is searched by patients from all over the world. If a volunteer is a preliminary match (odds of matching with someone outside your family range from one in 100 to one in 1 million), he or she is contacted by an NMDP local Donor Center. If the volunteer wishes to proceed and is a compatible match for a specific patient, the volunteer receives counseling and a physical exam before proceeding with the simple surgical procedure of marrow donation.

■ Once the NMDP reaches its goal of one million volunteers of diverse racial backgrounds, it expects to lose at least 10% of its volunteers each year due to age and health requirements. NMDP hopes that many of the 100,000 new volunteer donors needed each year to offset losses will come from the generosity and responsiveness of U.S. corporations which pay for employee tissue typing and offer a model of hope and help to the world.



Winter, 1992

TEN COMMON QUESTIONS ABOUT THE NATIONAL MARROW DONOR PROGRAM

1. What is the National Marrow Donor Program (NMDP)?

The National Marrow Donor Program (NMDP) is a network of transplant centers (which care for patients), donor centers (which guard our volunteer donors' safety and confidentiality), collection centers (medical centers which meet our standards for marrow collection) and recruitment groups (which assist the NMDP in recruiting new volunteers for the national registry; many NMDP donor centers also are aggressive recruitment arms of the NMDP).

The NMDP Coordinating Center and Registry are located in Minneapolis, MN. The NMDP is Congressionally authorized and has a contractual relationship with the National Heart, Lung, and Blood Institute.

NMDP has only been in existence since 1987 and has experienced rapid growth, especially in the last twelve months. This has been made possible because of the generosity of hundreds of thousands of Americans, willing to be the stranger who offers the living gift of life. NMDP is now facilitating about 40 transplants per month, up from 20 per month one year ago.

NMDP is also a research organization, studying the effectiveness of marrow transplants and related treatments. NMDP has created a "bank" of cell samples which has the potential for offering exciting insights into blood diseases and genetic disorders and is on the cutting edge of laboratory testing technology and biostatistical support.

NMDP is funded, in part, by Congress and also solicits charitable contributions for assistance in typing volunteers and other recruitment efforts. The National Heart Lung and Blood Institute has contracted with the NMDP to run a national registry. NMDP has also received funding from the Naval Medical Research and Development Command.

2. How many donors are on the Registry?

Almost 500,000 Americans have volunteered and are included in the registry.

Volunteering to be a donor is not appropriate for everyone because of the psychological and physical commitment required. Anesthesia is used when aspirating the marrow from the back of the pelvic bone. The discomfort felt after the donation has not been a major issue with donors (for a few days, there's a soreness described as similar to the feeling after falling on ice, on your derriere). The donor's marrow completely regenerates itself in a few weeks. However, because of the use of anesthesia, NMDP insists that all of its volunteer donors are between 18 and 55 and in excellent health.

The donor's commitment must be firm. A reversal in the decision after the patient begins preparing for transplant is life threatening for the patient. Many donors also become emotionally involved in following the progress of their patient post-transplant. Many of NMDP's volunteer donors have become strong advocates for the program. This gift of a stranger is called the "living gift of life."

2A. How many donors do you need to match all the patients who request a marrow transplant?

We do not know. Yet.

Depending on how common a patient's Human Leukocyte Antigens (HLA) are, the chances of finding a match may range from one in 100 to one in 1 million. The odds of finding a match are better within a patient's own racial group.

NMDP has set a preliminary goal of 100,000 donors for the United States and met that goal ahead of schedule. It became clear as we moved toward that goal that we would need more donors to match certain types of patients, especially those from American minority populations. It also has become clear that unrelated marrow transplants are a global hope. Because of computer technology, it is possible to have a worldwide registry of volunteers. Marrow can -- and has been -- exchanged between countries. NMDP has a goal of one million volunteer donors who represent a diversity of racial backgrounds. Because of the efforts of people all around the world, NMDP believes that its goal can be reached by 1995.

While NMDP's goal continues to be to find a "miracle match" for everyone who needs a marrow transplant, medical science may prove this to be impossible. Even with a large pool of potential donors, patients who have a rare or unique "HLA typing" may never find a match, no matter how large the pool of volunteer donors.

3. How many transplants have been done?

By January 1, 1992, NMDP had facilitated more than 1000 transplants, half of them for people under the age of 25. Of the patients receiving transplants, 77% had some type of leukemia. Other transplant patients have had Myelodysplasia, Hodgkin's lymphoma, Non-Hodgkin's Lymphoma, Severe Aplastic Anemia, Fanconi's Anemia, Osteopetrosis, Severe Combined Immunologic Deficiency, or other malignancies or non-malignant diseases.

Marrow transplants are being considered for patients with other types of cancer and other blood diseases. For example, research is being conducted to determine the efficacy of using marrow transplants to treat patients with Sickle Cell Anemia, and other genetic blood disorders. It is too early to speculate about the potential success or failure of these research efforts. NMDP officials continue to monitor these medical developments.

4. What is the success rate?

The standard answer is not a concise one. Early data indicated that the success rate is between 15 and 80 percent, depending on the disease of the patient being treated, stage of disease and age and condition of the patient. Without a transplant, long term survival is zero to 15 percent, but not usually over five percent.

Initially, many patients who chose transplantation made that choice after all other options had been exhausted or they had to wait a long time before a donor was identified. This resulted in less than physically ideal circumstances for the patient who may have been weakened by many rounds of chemotherapy or the disease itself.

The rigorous pre-transplant conditioning can be fatal. As marrow transplantation has become a more common treatment, patients are being referred for transplant earlier. In general, early referral and a "quick match" assures a better outcome for the patient. Although the data is preliminary, in the future, unrelated donor transplants may have the same success rate as

sibling transplants. With related donors, the chance of success can be as high as 80%, depending on the patient's disease and stage of disease at the time of transplant.

If the patient is alive and well three to five years after transplantation, the probability of disease coming back is remote. There are patients currently alive and well 20 years post transplant. NMDP's first transplant was done on December 15, 1987.

5. Does everyone who needs a transplant receive one and how much does it cost?

No, many patients are not referred for transplantation, currently cannot find a matched donor or are too ill to undergo a transplant once a match is found. Other patients are not insured or underinsured and cannot afford or choose not to undertake the expensive and exhausting process. Currently, NMDP is finding matches which result in transplant for 30% of the patients who search the NMDP Registry.

The cost ranges from \$150,000 to \$300,000. From initial studies, marrow transplantation is more cost efficient than maintenance or "palliative" procedures which must be undertaken numerous times. Also, a marrow transplant can cure if successful. For a leukemia patient or an aplastic anemia patient, other treatment usually only temporarily treats the symptoms of the disease.

Increasingly, health insurers are providing coverage/benefits for the cost of unrelated transplants as their experts review data on the successes achieved from this treatment. There is continuing concern over the hesitation by some payers to cover the donor search process and by some state governments to cover transplantation of any kind for medical assistance recipients.

Most of the cost of a transplant is the extended hospital stay in isolation until it is determined there is sustained engraftment of the new marrow. About 10% of the overall expense is the cost involving the NMDP donor. The search includes extended tissue typing (HLA typing)/cultures/donor counseling and a thorough donor physical exam, marrow collection and transport. NMDP continues to work with health care insurers to educate them about the procedure and why this portion of the cost should also be paid by the company.

A long term objective of the NMDP, through the Marrow Foundation, is to build a sufficient fund which can be tapped by patients who lack resources but need a transplant and have an identified donor.

6. Does NMDP encourage the efforts of individual families to increase the size of the registry?

Yes, with some qualifications -- and hope for the future.

With the help of Congress, the NMDP was established. The Program is hailed as a model for transplantation coordination and has progressed rapidly, exceeding all of our preliminary goals and expectations. Because of this success, many American families who held no hope for a loved one have now placed their hope in finding a match for the special person in need.

To build a satisfactory donor pool, NMDP is in need of three basic elements;

- A. More Americans willing to offer the "living gift of life" by volunteering to become a part of our Program. Currently, there is an especially critical need for minority volunteers.

- B. **The funds** (private and/or public) to pay for the typing test. It costs approximately \$75 to do partial typing of new recruits. Of all the challenges confronting NMDP, HLA test funding has been the toughest to surmount.
- C. **Time** to allow other countries to establish their own registries. This worldwide effort offers the best hope for patients seeking a matched donor. NMDP is vigorously encouraging development of registries in other countries.

While NMDP continues to seek private source funding to cover the significant HLA typing costs and to expand the registry internationally to allow for more diversity of the donor pool, the organization is also sensitive to the urgency felt by patients waiting today. Many families have launched local recruitment efforts when a matched donor was not immediately available through the registry.

NMDP encourages families to contact the NMDP Coordinating Center where staff members are available to advise families about where to call for help and how best to proceed. NMDP officials also maintain a strong sense of concern for both the patient and donor. This concern is integrated in the counsel given to families.

Because of the efforts of some families for their own loved one, the registry's volunteer pool continues to grow and other lives continue to be saved. This wonderful registry would not be possible if not for many determined families. Volunteers recruited in patient-specific drives sign consent forms which make them available to any patient searching for a matched donor.

The NMDP board continues to identify recruitment avenues, such as corporations and service clubs, to lessen the recruitment burden currently shouldered, in large part, by the families.

7. How are searches done with other countries?

International developments are one of the most exciting efforts underway at NMDP. Currently, 30 countries are in some way working cooperatively. Many of these countries are members of the NMDP or exchange searches with the NMDP. The establishment of the World Marrow Donor Association (WMDA) in December of 1990, which is presided over by the Nobel Laureate Dr. Donnall Thomas, gives great hope that a worldwide registry of volunteers is possible in the near future. The gift of marrow currently crosses national borders about once a month.

8. How long has NMDP been doing searches?

Since September, 1987. The first transplant was done in December, 1987. The 100th transplant was done in February, 1989; the 300th in March, 1990; the 500th in October, 1990; the 700th in May, 1991; the 1000th in December, 1991.

9. Why are you targeting minority communities for donor recruitment?

In the same way that you inherit your skin color or your hair color, you inherit your tissue type. This tissue typing must match between patient and donor to allow the best chance of success of the transplant.

For this reason, patients go first to their relatives when they are seeking a matched donor. About 25 percent of patients needing a transplant find a sibling match, most of the rest must turn their hope to NMDP. Chances of finding a matched stranger are best within one's own racial group.

Currently, 85 percent of the NMDP volunteer donors are Caucasian. It is of critical importance that NMDP reach members of minority communities and stress the urgent need for volunteer donors so the same hope can be offered to all Americans in need. Congress has made available special funds specifically for minority volunteer tissue typing. This funding is helping increase the racial diversity of the registry. While great progress has been made, there is still a great amount to be done to assure that the NMDP is a racially diverse resource. Until that time, NMDP is expected to continue to place a high priority on minority recruitment.

10. How do I become a donor?

- A. Give two tablespoons of blood and consent to be entered on the registry.
- B. Your blood is HLA or tissue-typed.
- C. Your HLA-type goes in the NMDP computer database where lab results are stored to be searched internationally by patients.
- D. A preliminary match is identified.
- E. Additional blood tests are requested to determine if you are a precise match for a specific patient in need.
- F. The miracle match is identified.
- G. After special counseling about donating marrow, you make the final decision to donate.

The NMDP has set up a network of NMDP donor centers (local blood bank organizations). Coordinators at these centers counsel potential donors and work with NMDP when someone is identified as a potential match. Only the donor center knows the name of a donor, assuring protection and anonymity of the donor. However, these donor centers are facing challenges and limitations of time, space and funding for typing. NMDP continues to assist these centers in overcoming these limitations.

Those who are interested in volunteering may contact their local donor center or call NMDP. In many communities, local drives are held, spearheaded by an individual family or one of NMDP's recruitment groups. Always, there is concern about raising the funds to pay for the HLA typing of those generous enough to volunteer as donors. Personal and corporate contributions and some funding from blood centers have been used in these efforts.

If a newspaper, television or radio station chooses to inform their audience about where to call for more information, NMDP's public toll-free number is 800/654-1247. For business-related calls to the NMDP, please call 800/526-7809.



Photo Courtesy SPENCER WEINER

Ina Kristiansen, right, and her mother, Virginia, wait in California for Ina's bone marrow transplant. Ina, a 22-year-old Anchorage woman who was diagnosed with acute myelitic leukemia in February, received her bone marrow from an anonymous donor.

Bone marrow donation is gift to Anchorage woman

By ANN CHANDONNET
TIMES WRITER

Ina Kristiansen will soon receive what could become a life-saving Christmas gift from a man she has never met.

Kristiansen, an Anchorage woman suffering from leukemia, learned on Christmas Eve that a donor had been found so that she can receive a bone marrow transplant at the UCLA Medical Center.

"This is the best Christmas present we ever got!" Ina's mother, Virginia Kristiansen, said Wednesday from her California hotel room.

Ina, 22, fell sick in February and was diagnosed with acute myelitic leukemia, a disease that disrupts the bone marrow's ability to produce normal blood cells.

Three possible donors who had Ina's Norwegian, Scot and Irish genetic background were found through the National Marrow Donor Program. Two were in England, the third, who will be the actual donor, was in the Uni-

'They're letting me stay in the hospital with her, sleeping in the same room. I'll be right there.'

— Virginia Kristiansen
patient's mother

ed States. Officials are withholding the name and other information about the donor until after the transplant.

Ina will enter the UCLA Medical Center this week for preliminary tests. The donor's marrow will be fed into her system beginning next week.

Meanwhile, her mother will be at her side. Virginia Kristiansen, a first-grade teacher at Tudor Elementary School, has taken a personal leave of absence from the Anchorage School District to be with her daughter.

"She needs someone to drive her from place to place because she is so weak," Kristiansen said. "They're letting me stay in the hospital with her sleeping in the

same room. I'll be right there."

Ina is a graduate of Service High School where she was a varsity soccer player. She plans to return to college as soon as she can. When she recovers from the transplant, she will come home — perhaps in April in May. In September, she wants to return to classes, her mother said.

"But she has been told to take it easy for six months after the transplant," she said.

Waiting and hoping has been hard on Virginia.

"I get my down moments, but we have to look at the positive. The positive is that Ina got this match. If she didn't have the match, things could be a lot worse."