

HCR

16

7-LS0977M
Lauterbach
2/4/92

CS FOR HOUSE CONCURRENT RESOLUTION NO. 16 (STATE AFFAIRS)

IN THE LEGISLATURE OF THE STATE OF ALASKA

SEVENTEENTH LEGISLATURE - SECOND SESSION

BY THE HOUSE STATE AFFAIRS COMMITTEE

Offered:
Referred:

CHANGES
HIGHLIGHTED

Sponsor(s): REPRESENTATIVES BRUCKMAN, Gruenberg, B.Davis, Carney

A RESOLUTION

1 Designating April 19 - 25, 1992, as "Bone Marrow Donor Week"; and requesting the
2 governor to proclaim an annual "Bone Marrow Donor Week."

3 **BE IT RESOLVED BY THE LEGISLATURE OF THE STATE OF ALASKA:**

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

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

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

11 **WHEREAS** the chances of finding a suitable unrelated bone marrow donor is between one in
12 20,000 and one in 1,000,000, depending on the patient's genetic make-up; and

13 **WHEREAS** there is a national bone marrow donor registry, established in 1987, to assist people
14 in finding a suitable donor from a pool of 470,000 "typed" volunteers ready and willing to donate their
15 life-giving marrow; and

16 **WHEREAS** there is an urgent, nationwide need to increase the pool to 1,000,000 available

1 marrow donors of all ethnic backgrounds to increase the chance of finding a suitable donor for the
2 10,000 people who are currently awaiting a bone marrow transplant throughout the United States and
3 who will die without a bone marrow transplant; and

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

6 **WHEREAS** the procedure for initial compatibility testing is considered completely safe and
7 virtually painless, requiring only two tablespoons of blood; and

8 **WHEREAS** Alaska currently has over 4,100 potential donors in the National Registry; and

9 **WHEREAS** in 1991, despite the staggering odds, Alaskan donors provided six bone marrow
10 matches, and three were provided for Alaskans requiring the marrow transplant through reciprocal
11 nationwide efforts through the National Bone Marrow Donor Program; and

12 **WHEREAS** the Blood Bank of Alaska has conducted successful bone marrow drives in
13 Anchorage, Juneau, Eagle River, Wasilla, Palmer, Fairbanks, McGrath, Kenai, Soldotna, and Hoonah
14 with drives scheduled for Kodiak and Dutch Harbor; and

15 **WHEREAS**, coupled with the aid of a special appropriation for type testing, numerous service
16 organizations throughout the state, spearheaded by the Eagle River Lions and Lionesses, have provided
17 countless hours in raising necessary funds and volunteering thousands of hours to conduct the drives
18 throughout Alaska and the ongoing efforts in Anchorage and Eagle River; and

19 **WHEREAS** in 1991 over 3,500 additional Alaskans were enrolled in the National Bone Marrow
20 Registry as a result of these efforts; and

21 **WHEREAS** a special outreach also helped enroll 126 Alaska Natives who were seriously
22 underrepresented in the National Registry and, as a result, were unlikely to find a successful match; and

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

26 **WHEREAS** with these initial efforts a minimum of one percent of Alaska's total population will
27 be enrolled in the Bone Marrow Donor Program;

28 **BE IT RESOLVED** that the Alaska State Legislature designates the week of April 19 - 25, 1992,
29 as "Bone Marrow Donor Week"; and be it

30 **FURTHER RESOLVED** that the legislature respectfully requests the governor to proclaim a
31 "Bone Marrow Donor Week" during an appropriate time period each year, setting the dates to correspond
32 with a nationally recognized week if there is one; and be it

1 **FURTHER RESOLVED** that the legislature encourages the commissioners of the state
2 departments, with the commissioner of health and social services taking the lead, to work in cooperation
3 with the Blood Bank of Alaska, Inc., to make continuing efforts to educate and inform state employees
4 and other Alaskans about the bone marrow donor program through newsletters, check stubs, and other
5 appropriate forms of communication.

WHILE IN SESSION
P.O. BOX V
JUNEAU, ALASKA 99811
(907) 465-4843



STATE AFFAIRS

REPRESENTATIVE BETTY BRUCKMAN

Sponsor Statement

HCR 16

'Designating April 14 - 20, 1992, as Bone Marrow Donor Week'

I have introduced HCR 16 to increase awareness and to educate the general public regarding bone marrow transplants as well increase enrollment in the National Marrow Donor Program.

HCR 16 designates the week of April 14 - 20, 1992 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.

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 rarer, 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.





REPRESENTATIVE BETTY DRUCKMAN

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CS HCR 16

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CS HCR 16 designates the week of April 14 - 20, 1992 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. I would appreciate the committee's consideration of this CS, changing the date from April 12 - 18, 1992 to April 19 - 25, 1992, to conform with National Organ Procurement Week. Language has also been added to update the statistics as they relate to Alaskans enrolled in the National Marrow Registry.

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 rarer, 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.

Although the bone marrow donor program is an ongoing effort, designating one week in April will help increase the level of public awareness and facilitate promotional activities.

STATE OF ALASKA
1992 LEGISLATIVE SESSION

No. 1
Bill Version: CSHCR 16 (HES)
(H) Publish Date: 1/24/92
LEGISLATURE

Revision Date: _____ Department Affected: _____
Title: DESIGNATING APRIL 12-18 BRU: _____
BONE MARROW DONOR WEEK Component: _____
Sponsor: BRUCKMAN
Requestor: _____ 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 | | | | | | |
| TRAVEL | | | | | | |
| CONTRACTUAL | | | | | | |
| SUPPLIES | | | | | | |
| EQUIPMENT | | | | | | |
| LAND & STRUCTURES | | | | | | |
| GRANTS, CLAIMS | | | | | | |
| MISCELLANEOUS | | | | | | |
| TOTAL OPERATING | -0- | | | | | |
| | | | | | | |
| CAPITAL | -0- | | | | | |
| | | | | | | |
| REVENUE | -0- | | | | | |
| FUND SOURCE: | | | | | | |

FUNDING: (Thousands of Dollars)

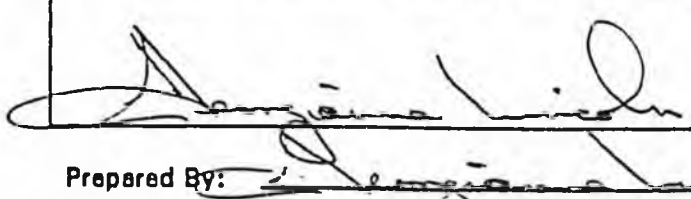
| | | | | | | |
|---------------|-----|--|--|--|--|--|
| GENERAL FUND | -0- | | | | | |
| FEDERAL FUNDS | -0- | | | | | |
| OTHER | | | | | | |
| FUND SOURCE: | -0- | | | | | |
| TOTAL | -0- | | | | | |

POSITIONS:

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

Estimate of current year impact: _____

ANALYSIS: (Attach a separate page if necessary.)

Prepared By:  Phone: 465-3732
Division: HOUSE HEALTH, EDUCATION & SOCIAL SERV. COMMITTEE Date: 1/21/92
Approved by Commissioner: _____
Agency: _____ Date: 1/21/92

HOUSE COMMITTEE REPORT

(7)

Date Referred: March 13, 1991

FURTHER REFERRALS:

State Affairs

Date of Committee Action: _____

The HEALTH, EDUCATION AND SOCIAL SERVICES Committee considered:

HCR 16

HOUSE CONCURRENT RESOLUTION NO. 16

BONE MARROW DONOR WEEK

Designating April 14 - 20, 1991, as "Bone Marrow Donor Week."

RECOMMENDATIONS: COMMITTEE [] the same title
 be replaced with SPONSOR SUBSTITUTE FOR [] a new title

[] have attached amendments(s)

HCR 16 (HES)

[] do pass

[] do not pass

[] no recommendations

[] individual recommendations

[] additional referral to the _____ Committee

ADOPTS: _____ letter of Intent

ATTACHES NEW FISCAL NOTE(S): (Dept)

APPROVES PREVIOUS: (Dept/Date)

[] fiscal impact _____

[] fiscal note(s) _____

[] zero fiscal note HOUSE HESS

[] zero fiscal note(s) _____

| SIGNING <u>DO</u> PASS | DP | OTHER RECOMMENDATIONS | DNP | NR | AM |
|----------------------------|----|-----------------------|-----|----|----|
| <i>[Signature]</i> | ✓ | | | | |
| <i>[Signature]</i> | | | | | |
| <i>Betty Kaurig</i> | ✓ | | | | |
| <i>John C. [Signature]</i> | | | | | |
| <i>Cheri Davis</i> | ✓ | | | | |
| <i>Mark [Signature]</i> | X | | | | |
| <i>Mary Miller</i> | ✓ | | | | |
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SIGNATURE



9/17/90

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 (who care for patients), Donor Centers (who 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 is located in St. Paul, MN and the computerized Registry is at the University of Minnesota. The Registry is the most sophisticated biometric program ever run by the U of M and is one of the most sophisticated 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 and has experienced rapid growth, especially in the last six 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 now is facilitating about 25 transplants a month. Admiral Zumwalt, NMDP Chairman of the Board has stated that the goal is 25 transplants a day.

We are also a research organization, studying the efficacy of marrow transplants and related treatments. NMDP has created a "bank" of cell line samples which has the potential for offering exciting insights into blood diseases and genetic disorders.

NMDP is funded, in part, by Congress through the National Heart, Lung and Blood Institute (part of the National Institutes of Health). The NMDP also solicits charitable contributions for assistance in typing volunteers and other recruitment efforts.

2. How many donors are on the Registry?

By the middle of September, 1990, over 200,000 people have volunteered and are included in the Registry. That number is doubled when you include volunteer donors from other countries, and it is expected to continue to grow nationally and internationally.

Volunteering to be a donor is not appropriate for everyone because of the commitment of time (about 40 hours in all, including counseling sessions, a complete physical and the approximately 24 hour hospital stay) and the need to use anesthesia 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). However, because of the anesthesia factor, NMDP insists that all of its volunteer donors are between 18 and 55 and in excellent health. Many of NMDP's volunteer donors have become strong advocates for the Program.

Marrow completely regenerates itself in about 15-30 days. That's why 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 don't 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 a million. The odds of finding a match are better within a patient's own racial group.

NMDP 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 worldwide; 250,000 volunteers is NMDP's new U.S. goal. The U.S. goal includes expanding the ethnic diversity of this nation's registry to reflect the diversity of the country's population. 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 the end of July, 1990, NMDP will have facilitated over 400 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 (6.8%), 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, AIDS 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's the Success Rate?

The standard answer is not a concise one. Early data indicate that the success rate is between 30 and 80 percent, depending on the disease of the patient being treated, stage of disease and age and condition of the patient.

Initially, many patients who chose transplantation made that choice after all other options had been exhausted. 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, it appears that unrelated donor transplants may have the same success rate as sibling transplants. With related donors, the chance of success can be as high as 90%, 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 transplant, the probability of disease coming back is remote. There are patients currently alive and well nineteen years post transplant. Among patients receiving unrelated donor transplants, the longest living survivor is over seven years post transplant. NMDP's first transplant was done on December 15, 1987. It will be at least two to three years before NMDP can offer definitive numbers regarding success rate.

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

No, many patients are not referred for transplant, 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 exhaustive process. Currently, NMDP is finding matches which result in transplant for 20% of the patients who search the NMDP Registry.

The average cost is approximately \$150,000. 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 stay in isolation until it is determined there is sustained engraftment of the new marrow. About 10% of the overall expense is the cost of actually searching for an unrelated donor. The search includes extended tissue typing (HLA typing)/cultures/donor counseling and a thorough 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.

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

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 minorities to volunteer.
- B. The funds (private and/or public) to pay for the typing test. It costs approximately \$65-\$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 Common Questions

Page 5

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 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 moms and dads."

Volunteers recruited in patient-specific drives sign consent forms which make them available to any patient searching for a matched donor.

7. How are searches done with other countries?

International developments are one of the most exciting efforts underway at NMDP. Currently, The Netherlands is, and Israel will soon be, a part of NMDP's computer registry. Searches are "traded" (usually by facsimile) with the United Kingdom, Canada and France. NMDP anticipates that other European countries will become affiliated with the U.S. registry within the next six months. Japan and the Soviet Union are also considering creating a registry, and informal requests have come from many other nations offering opportunities for communications across political boundaries.

8. How long have you been doing searches?

Since September, 1987. The first transplant was done in December, 1987. The 100th transplant was done in February, 1989; the 200th in October, 1989; the 300th in March, 1990.

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, the rest must turn their hope to NMDP.

Currently, 92 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.

10. How do I become a donor?

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 grassroots groups such as Heart of America, NMDP's Donor Center Without Walls. 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 1-800/654-1247. For business-related calls to the NMDP, please call 800/526-7809.

C.W. BILL YOUNG
8TH DISTRICT, FLORIDA

MEMBER:
COMMITTEE ON
APPROPRIATIONS
SUBCOMMITTEE ON
NATIONAL DEFENSE

Congress of the United States
House of Representatives
Washington, DC 20515
August 2, 1991

3407 RAYBURN BUILDING
WASHINGTON, DC 20515

DISTRICT OFFICE:
SUITE 827
144 FIRST AVENUE, SOUTH
ST. PETERSBURG, FL 33701

SUITE 808
801 WEST BAY DRIVE
LARGO, FL 34840

The Honorable Betty Bruckman
State Representative
House of Representatives
PO Box V
Juneau, Alaska 99811

Dear Representative Bruckman:

A miraculous life-saving movement is sweeping across our nation as more than 30,000 volunteers per month are becoming a part of the National Marrow Donor Program.

In the six short years since its inception, 370,000 Americans have taken the quick and simple blood test to join a registry of potential marrow donors for patients suffering from leukemia or any one of 60 otherwise fatal blood disorders. Through this national registry, 40 men, women, and children per month, who otherwise had no hope for life, are now finding matched donors who can provide a small amount of marrow that offers them the chance of a lifetime.

Although the program has been an unquestioned success, there is still much more that needs to be done if we are to find matched donors for the estimated 24 patients per day who are in need of a transplant. The keys to our success are people who are willing to volunteer to help us reach our goal of a national registry of 1 million potential donors. This is critical because with the odds of finding a matched donor anywhere from one in 100 to one in one million, the chances of finding a match grow as the pool of potential donors grows.

The United States Congress, and the House Appropriations Committee on which I serve, recognized the tremendous potential for this program as we established the national registry in 1987 and have appropriated more than \$85 million since then for its operations. In particular, we responded to the pleas of families and recruitment organizations around the country by providing federal funding to defray the \$75 lab costs for the blood test of each volunteer. Our Committee appropriated almost \$40 million for this purpose during a six month period last summer and fall. A major portion of these funds are being used to target minority populations which are seriously under-represented in the registry. Because your marrow type is based upon your genetic background,


which you inherit from your parents just like your eye, hair, and skin color, it is more than likely that a matched marrow donor will be someone with the same genetic or ethnic background.

While the federal government has played a major role in the establishment and funding of the National Marrow Donor Program, there is still much that can and must be done at the state and local level to increase awareness about the national registry, to encourage more Americans to volunteer, to enhance minority recruitment, and to ensure that when matched donors are found for patients, a transplant is not prevented from taking place because the donor is unable to take time off from work. A number of states have passed legislation which will be very helpful in supplementing the work of the national program. Minnesota and Oregon, in particular, have enacted comprehensive bills that establish state-wide programs to educate residents about the program, that authorize donor recruitment drives for state employees, and that require businesses to guarantee employees up to 40 hours of paid leave for the purpose of donating marrow. The Oregon bill also authorizes a tax credit of 25 percent to compensate businesses for the cost related to an employee's time off necessary to donate marrow. Enclosed is a summary of the Minnesota and Oregon legislation, as well as the actions taken by 12 other state legislatures, which I would encourage you to study and consider sponsoring in your own state.

In a related matter, you may be interested to know that during the National Conference of State Legislatures Annual Meeting August 11-16 in Orlando, Florida, the National Marrow Donor Program will sponsor a booth to provide you with more information about the program. A summary of activity by various state legislatures and copies of the Minnesota and Oregon laws will be available for you to pick up as well as a packet providing greater detail about the program. You also will have the opportunity to volunteer for the national registry by taking the quick and simple blood test right there at the booth.

The National Marrow Donor Program is a national and international treasure that is saving lives throughout the world. Being involved with this modern medical miracle has been one of the most rewarding experiences of my whole life and I look forward to working with you to further expand our efforts to save lives. Please do not hesitate to contact me if you would like copies of specific state legislation or if you would like more detailed information about the program or sponsoring donor recruitment programs in your district. Thank you for your interest, and with best wishes and personal regards, I am

Very truly yours,


C. W. Bill Young
Member of Congress

CWY:hg
Enclosure

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

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 an-

nounced 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

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-



BONE MARROW RECIPIENT JAY GIBSON AND DONOR DANNY STOREY

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

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*

PHOTOGRAPH BY MICHAEL L. ABRAMSON