Department of Health and Human Services

OFFICE OF INSPECTOR GENERAL

NATIONAL MARROW DONOR PROGRAM

PROGRESS IN MINORITY RECRUITMENT

JUNE GIBBS BROWN
Inspector General

DECEMBER 1996

OEI-01-95-00120

OFFICE OF INSPECTOR GENERAL

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OEI's Boston Regional Office prepared this report under the direction of Mark R. Yessian, Ph.D., Regional Inspector General. Principal OEI staff included:

Boston Region
Russell W. Hereford, Ph.D., *Project Leader*
Elizabeth Robboy, *Program Analyst*

Headquarters
Alan Levine, *Program Specialist*

To obtain a copy of this report, contact the Boston Regional Office by telephone at (617) 565-1050 or by fax at (617) 565-3751.

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EXECUTIVE SUMMARY

PURPOSE

To assess the performance of the National Marrow Donor Program in increasing the representation of potential donors from racial and ethnic minority groups on the registry of volunteer unrelated marrow donors.

BACKGROUND

Bone marrow transplantation is a treatment for blood borne diseases such as leukemia and lymphoma. For a transplant to be successful, the patient's and donor's blood cell proteins, referred to as human leukocyte antigens, must match as closely as possible. Because different populations have quite different genetic traits, it is much more likely that a patient will find a match from within his or her own racial group.

The National Marrow Donor Program (NMDP), is a nonprofit organization based in Minneapolis, Minnesota, that finds matching donors for patients seeking a transplant. It operates the congressionally authorized marrow donor registry under contract with the Health Resources and Services Administration (HRSA). One major function of the registry is to "increase the representation of individuals from racial and ethnic minority groups."

The NMDP accredits local donor centers that recruit volunteers to join the registry. As of October 1995, the registry contained almost 1.5 million donors from 97 domestic centers. It also has accredited 11 recruitment groups to help recruit minority donors. This report is based on mail surveys of 88 of the 97 domestic donor centers and all 11 recruitment groups; statistical data maintained by NMDP; and site visits to 9 donors centers and 4 recruitment groups across the country.

FINDINGS

The number and proportion of donors on the registry from racial and ethnic minority groups has grown substantially. However, the proportion of black donors and Hispanic donors still falls short of their representation in the U.S. population.

In the two and one-half years between April 1993 and October 1995, the number of donors from racial and ethnic minority groups increased by 180 percent, from 127,663 to 356,420. Minority donor representation on the registry grew from 17 percent to 25 percent.

The NMDP reached the goals specified in its contract with HRSA regarding minority recruitment for the year May 1994-April 1995, with the exception of Hispanic recruitment, where it fell short by about 20 percent (7,000 donors).

As of October 1995, blacks comprised 9 percent of donors on the registry (vs. 12 percent in the general population), and Hispanics comprised 8 percent of donors on the registry (vs. 9 percent in the general population).

Even as donor centers' recruitment of minorities has increased, the overall retention rate for these donors has remained about the same. However, retention rates among donors from racial and ethnic minority groups continue to lag behind those for whites.

Few donor centers have a proportion of minority donors that equals or exceeds the proportion of minorities living in their service area. The NMDP, however, does not have in place performance indicators to measure individual donor centers' progress in recruiting minorities.

Seventy-four of the 97 donor centers had a smaller proportion of Hispanics on their lists than reside in their service areas. Sixty-five donor centers had a smaller proportion of black donors than reside in their service areas.

The distribution of minority donors is concentrated in a few donor centers. Twelve donor centers accounted for more than 50 percent of all donors from minority groups.

Donor centers responding to our survey identified three major obstacles to recruitment of minorities to the national registry:

Lack of awareness of marrow donation among minorities
Mistrust of marrow donation among minority groups
Language and/or cultural barriers

The NMDP has developed strategies to overcome these obstacles. Each of these strategies, however, contains some vulnerabilities that may limit their effectiveness.

Publications. Eighty-six of the 88 donor centers responding to our survey report that they are using materials prepared by NMDP to increase awareness and decrease mistrust about marrow donation among minorities. However, during our site visits, donor center and recruitment group staff raised concerns about these materials' sensitivity to local conditions and, in some cases, the accuracy of translation.

Recruitment Groups. Thirty-nine of the 88 donor centers responding to our survey reported that they work with NMDP-accredited recruitment groups as one way of overcoming language and cultural barriers. Seventeen centers reported that they rely on these recruitment groups for more than half of their minority recruitment. Despite turning to recruitment groups to play a major role in recruiting minority donors, NMDP does not have in place performance indicators to measure their ongoing effectiveness.

RECOMMENDATIONS

Performance Indicators for Donor Centers. In the next contract, the Health Resources and Services Administration should require that the National Marrow Donor Program develop and implement performance indicators that measure the progress of individual donors centers in recruiting donors from racial and ethnic minority groups. We urge that these indicators be implemented within the first year of the new contract.

Performance Indicators for Recruitment Groups. In the next contract, the Health Resources and Services Administration should require that the National Marrow Donor Program develop and implement performance indicators that measure the accomplishments of recruitment groups. We urge that these indicators be implemented within the first year of the new contract.

Contingency Plans. The HRSA should identify steps to be taken should the NMDP continue to fall short on the recruitment goals specified in its current contract, as occurred among Hispanic donors in the first year.

Sharing Effective Practices. The NMDP should draw on the expertise of those donor centers and recruitment groups that have succeeded in recruiting minority donors as one way of providing assistance to other donor centers.

COMMENTS ON THE DRAFT REPORT

The Health Resources and Services Administration (HRSA), the Assistant Secretary for Health (ASH), and the National Marrow Donor Program (NMDP) commented on the draft report.

HRSA concurs with our recommendations regarding performance indicators, except that the agency believes it is not possible to implement these indicators before signing the next contract. We agree that more time might be needed. We changed our recommendations to require the NMDP to develop and implement these indicators in the next contract. We continue to believe that developing, implementing, and enforcing performance standards for recruitment of donors from minority groups and for performance of recruitment groups are important, and need to be accomplished as quickly as possible.

NMDP's comments were similar to HRSA's. In our view, all donor centers have a role to play in improving the chances for minority patients awaiting transplant to find a donor. For this reason, we recommend some type of linkage between recruitment goals and the minority population in each donor center's service area.

The Assistant Secretary for Health comments that the recommendations contained in this report are important and should be implemented as quickly as possible. We have changed the language in the report in several places as ASH recommends.

TABLE OF CONTENTS

INTRODUCTION

PURPOSE:

To assess the performance of the National Marrow Donor Program in increasing the representation of potential donors from racial and ethnic minority groups on the registry of volunteer unrelated marrow donors.

BACKGROUND:

Bone Marrow Transplantation

Bone marrow transplantation is a treatment for blood borne diseases such as leukemia and lymphoma. About 16,000 people are diagnosed each year with leukemia and other fatal blood diseases.[1] Many of these people could benefit from a bone marrow transplant, a procedure in which the patient's diseased bone marrow is destroyed and marrow from a healthy donor is infused into the patient's blood stream. Bone marrow produces platelets, red blood cells, and white blood cells, the agents of the body's immune system. For a bone marrow transplant to be successful, the patient's and donor's antigens must match as closely as possible. About 30 percent of the time the patient has a sibling with matching antigens. In the other 70 percent of cases the patient must seek an unrelated donor.

Three pairs of blood cell proteins, known as the Human Leukocyte Antigen (HLA) -A, -B and -DR, are important in determining whether a match will be successful. One antigen in each pair is inherited from an individual's mother, the other from the father. Because there are numerous antigens at each HLA-A, -B, -DR locus, more than 600 million combinations are theoretically possible.[2]

The National Marrow Donor Program

The National Marrow Donor Program (NMDP) is a non-profit organization based in Minneapolis, Minnesota. The NMDP operates the Congressionally authorized marrow donor registry under contract with the Health Resources and Services Administration (HRSA). The contract is funded at $40,471,000, from July 1994 through April 1997.

The registry's major functions are to: (1) establish a system for finding marrow donors suitably matched to unrelated recipients for bone marrow transplantation; (2) recruit potential donors; and (3) increase the representation of individuals from racial and ethnic minority groups in order to enable an individual in a minority group, to the extent practicable, to have a comparable chance of finding a suitable unrelated donor as would an individual not in a minority group.[3]

The NMDP began operations in September 1987 as a non-profit organization funded through a contract from Office of Naval Research. The NMDP was created through a cooperative effort of the American Association of Blood Banks, American Red Cross, and Council of

Community Blood Centers. The NMDP began search operations with 10 transplant centers, 49 donor centers and 8,000 donors listed on the registry. As bone marrow transplantation came to be seen as viable technique, the U.S. Navy recognized that it was inappropriate for the military to maintain a civilian registry. In 1989, responsibility for the contract was transferred to the National Heart, Lung, and Blood Institute in the National Institutes of Health. Contract oversight for the NMDP was again transferred in 1994 to HRSA in recognition that NMDP was a service delivery program, rather than a basic research initiative.

Donor Recruitment

Recruiting volunteer donors, particularly minority donors, is a major responsibility of the registry. The NMDP accredits local donor centers that recruit volunteers to join the registry. As of October 1995, the registry contained almost 1.5 million donors in 97 domestic donor centers, and an additional 450,000 donors from 6 foreign centers. Eighty-one of the domestic centers are blood centers, either Red Cross-affiliated or part of community blood centers; 13 centers are departments of hospitals, and 3 are free-standing centers. Six of the domestic centers have more than 50,000 donors on their list; another 35 centers have between 10,000 and 50,000 donors each. The remaining 56 centers have fewer than 10,000 donors.

The NMDP also has accredited 11 recruitment groups to help recruit donors. Because of their ties to particular segments of the local community, recruitment groups theoretically are able to recruit donors from those segments with more success than donor centers. Upon recruiting a potential donor, the recruitment group must "turn over" the donors it has recruited to the donor center with which it works. In the event that one of these donors is needed for further testing leading to actual donation, the affiliated donor center is responsible for all contact with the donor.

Issues in Minority Recruitment

Even with a registry of 1.5 million donors, it remains difficult for minority patients to find matching donors. This problem is particularly acute for African-Americans, due to the increased number of HLA combinations occurring in this group. Consequently, the legislation establishing the registry requires it to "increase the representation of individuals from racial and ethnic minority groups ... in order to enable an individual in a minority group, to the extent practicable, to have a comparable chance of finding a suitable unrelated donor as would an individual not in a minority group."[4] Of the 3,198 transplants that the NMDP has facilitated since it began operations in September 1987, less than 10 percent were for minority patients.

Previously, the Office of Inspector General examined racial disparities in access to donated solid organs (*The Distribution of Organs for Transplantation: Expectations and Practices*, OEI-01-89-00550, March 1991). In that report, we found that blacks on kidney waiting lists wait almost twice as long as whites for a first transplant. There has been some improvement in access to organs among minorities. In 1994, 39 percent of recipients of cadaveric kidneys were minorities, versus 35 percent in 1988. The percentage of cadaveric kidney donors who

were minorities increased in that same time period from 16 percent to 22 percent.[5]

Bone marrow transplantation differs from solid organ transplantation in many important respects. However, both procedures require compatibility in donor and recipient human leukocyte antigens to improve chances for a successful match. Because the combination of blood cell proteins tends to follow racial and ethnic lines, a patient has the best chance of finding an appropriate donor from within his or her own racial group.

In a 1992 report, the General Accounting Office (GAO) found that the proportion of black and Hispanic potential donors for marrow donation still lagged considerably behind their proportions in the U.S. population. The GAO recommended that for the NMDP to achieve its goal of a representative racial and ethnic distribution, the NMDP would have to at least double the proportion of blacks and Hispanics on the Registry.[6]

SCOPE AND METHODOLOGY:

This report addresses the 97 domestic donor centers. The report is one of four companion reports addressing the National Marrow Donor Program. The other three reports are: *National Marrow Donor Program: Effectiveness in Retaining Donors* (OEI-01-95-00121); *National Marrow Donor Program: Geographic Overlap Among Donor Centers* (OEI-01-95-00122); and *National Marrow Donor Program: Financing Donor Centers* (OEI-01-95-00123).

This report is based on five primary data sources:

1) The NMDP'S registry statistics extending over a two and one-half year period, from April, 1993 through October, 1995.

2) A mail survey of the 97 domestic donor centers. We received 88 responses, a response rate of 91 percent.

3) 1990 U.S. Census Data at a county level.

4) The NMDP's Donor Center Access Directory, in which each donor center displays a map of the geographic area that it covers.

5) Site visits to donor centers and recruitment groups in California, Massachusetts, Minnesota, New Jersey, North Carolina, and South Carolina.

Appendix B provides a more detailed description of our methodology.

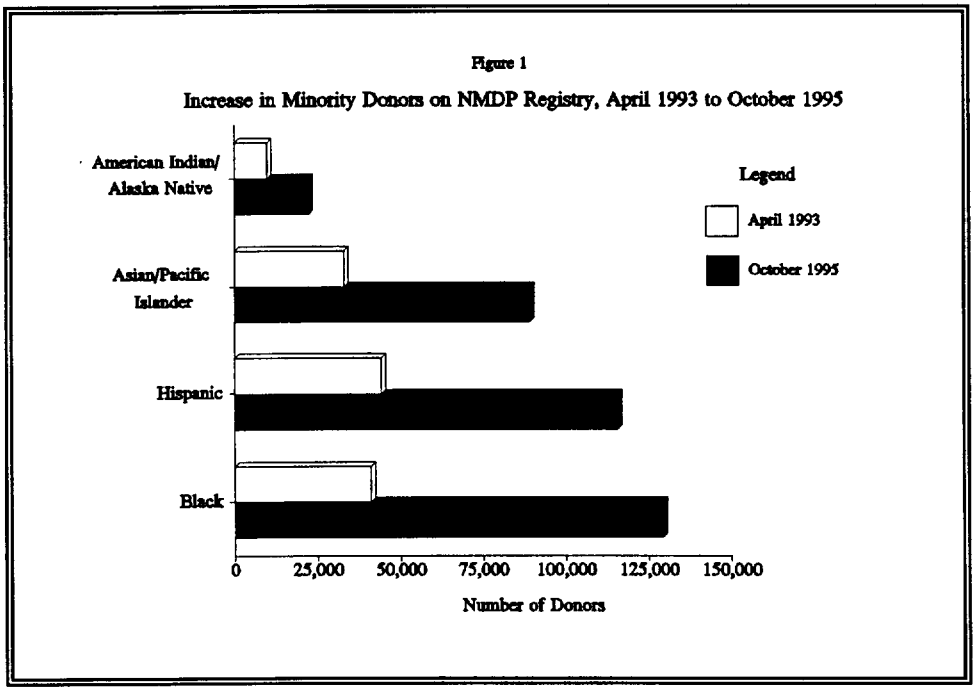
We conducted this study in accordance with the *Quality Standards for Inspections* issued by the President's Council on Integrity and Efficiency.

FINDINGS

THE NUMBER AND PROPORTION OF DONORS ON THE REGISTRY FROM RACIAL AND ETHNIC MINORITY GROUPS HAS GROWN SUBSTANTIALLY. HOWEVER, THE PROPORTION OF BLACK DONORS AND HISPANIC DONORS STILL FALLS SHORT OF THEIR REPRESENTATION IN THE U.S. POPULATION.

- ***In the two and one-half years between April 1993 and October 1995, the number of donors from racial and ethnic minority groups increased by 180 percent, from 127,663 to 356,420. Minority donor representation on the registry grew from 17 percent to 25 percent.***

The NMDP tracks five broad racial and ethnic categories of donors: White, black, Hispanic, Asian/Pacific Islander, and American Indian/Alaska Native donors.[7] The NMDP considers the non-white donors to be minority donors. The total number of donors on the registry grew by 91 percent, from 757,769 to 1,447,324, in the two and one-half years between April 1993 and October 1995. Minority donors accounted for about one-third of that increase. The number of white donors increased by 77 percent, from 595,942 to 1,054,396.



In our site visits to donor centers and NMDP headquarters, we heard of two overarching reasons for the growth of minority donors on the registry. The first reason is a general emphasis on the need for more minority donors in order to make bone marrow transplantation available to patients from minority groups. One way in which the NMDP promotes awareness is through national campaigns directed at specific minority groups. The NMDP has launched two such campaigns thus far, one targeted at black donors and the other

targeted at Asian/Pacific Islander donors.[8] The NMDP also emphasizes the need for a diverse registry through promotional literature and brochures aimed at the general public.

The second reason for the growth of minority donors on the registry is the financial incentives built into the system. A grant from the Department of Navy pays for tissue typing of minority donors. White donors who wish to volunteer for the registry must pay the cost of tissue typing themselves, or through privately generated funding. These typically range from $45 to $60 for the initial HLA -A and -B typing.

More recently, the NMDP has begun paying donor centers a higher fee for recruiting minority donors than for white donors. The NMDP pays the 62 donor centers reimbursed on a fee-for-service basis $28 for each new minority donor and $10 for each new white donor. The other 35 donor centers, which are funded on contract basis, have funds earmarked for minority recruitment staff.

- ***The NMDP reached the goals specified in its contract with HRSA regarding minority recruitment for the year May 1994-April 1995, with the exception of Hispanic recruitment, where it fell short by about 20 percent (7,000 donors).***

The NMDP'S 3-year contract with HRSA stipulates that 150,000 new donors must be recruited annually. At least 30,000 of these new donors should be black, 18,800 should be Asian/ Pacific Islander, and 32,000 should be Hispanic. The contract does not specify an annual recruitment goal for American Indian/Alaska Natives. Table 1 compares the level of NMDP minority recruitment with HRSA recruitment goals. The table also presents data on recruitment for the first half of this second contract year.

Table 1
MINORITY GOALS SPECIFIED IN HRSA CONTRACT

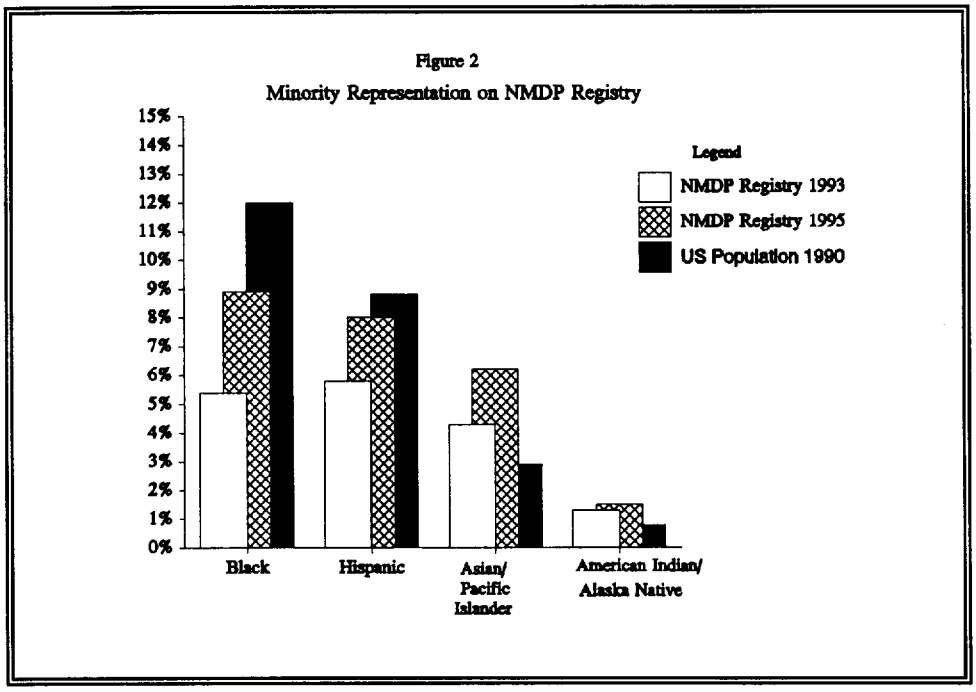
Racial/Ethnic Group	Number of donors recruited by NMDP between May 1, 1994 and April 30, 1995	Annual recruitment level specified in the HRSA contract	Difference between the HRSA contract and the actual level of recruitment	Number of donors recruited by NMDP between May 1, 1995 and October 31, 1995
Blacks	38,275	30,000	8,275	20,183
Asian/Pacific Islanders	22,492	18,800	3,692	14,194
Hispanics	25,147	32,000	(6,853)	17,183
All Donors	288,989	150,000	138,989	142,109

Data Source: NMDP Registry Statistics, April 1994 through October 1995.
Analysis: Office of Inspector General (OIG).

The absence of a national campaign targeted on Hispanic donors may provide one explanation for NMDP's limited success in recruiting Hispanic donors as compared to their success with donors from other minority groups. However, the NMDP reports that plans are underway for a national campaign that targets Hispanic donors in four areas of the country.[9]

- ***As of October 1995, blacks comprised 9 percent of donors on the registry (vs. 12 percent in the general population), and Hispanics comprised 8 percent of donors on the registry (vs. 9 percent in the general population). These proportions represent substantial increases, from 5 percent for blacks and 6 percent for Hispanics in April 1993.***

As figure 2 depicts, the proportion of Asian/Pacific Islanders and American Indian/Alaska Natives on the registry already exceeds their proportion in the population. Asian/Pacific Islanders account for 6 percent of the donors on the registry (vs. 3 percent in the general population); American Indian/Alaska Natives account for 2 percent (vs. 1 percent in the population).



For this analysis we compared the percent of minority representation in the registry with 1990 U.S. population census data. This analysis is conservative for two reasons. First, the number of blacks and Hispanics may be under represented in the 1990 U.S. census.[10] Second, because of the 5-year gap between the 1990 census and the 1995 NMDP statistics, minorities may account for an even higher proportion of the U.S. population today. As a result, the disparity between the proportion of minorities on the registry vs. those in the U.S. population may be even wider than reported here.

Even as donor centers' recruitment of minorities has increased, the overall retention rate for these donors has remained about the same. However, retention rates among donors from racial and ethnic minority groups continue to lag behind those for whites.

- Retention of minority donors at first level follow-up testing (DR typing) improved to 66 percent for the year ending September 1995, up from 55 percent for the year ending September 1993.

- However, retention of minority donors at second level follow-up testing (CT testing) declined to 60 percent for the year ending September 1995, down from 67 percent for the year ending September 1993.

Donor retention rates measure the proportion of donors who proceed to followup testing, when their names appear as potential matches. In our companion report, *National Marrow Donor Program: Effectiveness in Retaining Donors* (OEI-01-95-00121), we examine donor retention in detail.[11] Among white donors, the retention rate at DR was 76 percent for the year ending September 1995; the CT retention rate was 81 percent.

As we discuss in the companion report, a likely important explanation for the increase at DR testing and decline at CT testing is the recently initiated practice of DR-typing virtually all minority donors at registration. As a result, the difficulties associated with contacting and obtaining permission for donors that previously were found at DR-typing are now arising at CT.

The lower retention rate among minority donors has important implications for recruitment of donors from these groups. The large number of HLA combinations among some minority groups makes it difficult for patients from these groups to find a matching donor; in itself, this means that donors from these groups need to be over-represented on the registry to provide an equitable chance of finding a match. Second, the lower retention rate means that an even greater number of donors from these groups is needed in order to find a match who is willing to proceed all the way to actual marrow collection and transplant.

FEW DONOR CENTERS HAVE A PROPORTION OF MINORITY DONORS THAT EQUALS OR EXCEEDS THE PROPORTION OF MINORITIES LIVING IN THEIR SERVICE AREA.

- ***As of October 1995, 74 of the 97 donor centers had a smaller proportion of Hispanics on their lists than reside in their service areas. Sixty-five donor centers had a smaller proportion of black donors than reside in their service areas.***

We compared the service area of each donor center at the county level with county level population data from the 1990 U.S. Census.[12] We then compared the percent of minority donors on each donor center's list with the percent of minority donors residing in their service area. Table 2 (following page) depicts the number of donor centers falling short of or exceeding the proportion of minorities in their service area.

Table 2

DONOR CENTERS IN WHICH THE PROPORTION OF MINORITIES ON THEIR LISTS EXCEEDS OR FALLS SHORT OF THEIR REPRESENTATION IN THE LOCAL SERVICE AREAS

Ethnic and Racial Group	Number of donor centers with lists ***falling short*** of the proportion of minorities in their service areas	Number of donor centers with lists ***exceeding*** the proportion of minorities in their service areas
Hispanic	74	22
Black	65	31
Asian/Pacific Islander	38	58
American Indian/Alaska Native	31	65

N=96 Donor Centers. Excludes U.S. Navy's Bill Young Marrow Donor Center because of that center's unique focus on military personnel worldwide.

Data Source: NMDP Registry Statistics for October 31, 1995; donor center service areas defined in NMDP's "Donor Center Access Directory" for October, 1995; and 1990 U.S. Census Population Data.

Analysis: Office of Inspector General (OIG).

We further analyzed the donor centers' lists to determine the extent to which centers fall short on minority recruitment. Our analysis shows that 27 donor centers had lists which reflected less than half the percentage of Hispanics in their service areas. Thirty donor centers had lists which reflected less than half the percentage of blacks in their service areas. Twelve donor centers had lists which reflected less than half of the percentage Asian/Pacific Islanders in their service areas, and seven donor centers had lists which reflected less than half of the American Indian/Alaska Natives in their service areas.

Our analysis revealed that 11 donor centers had lists which fell short of the proportion of minorities in their service area for all 4 minority groups. Five centers had donor lists which reflected or exceeded the proportion of all minority groups in their service area. We did not find anything particular about either of these two groups. However, in our companion report *National Marrow Donor Program: Financing Donor Centers* (OEI-01-95-00123), we report that contract centers are more likely than fee-for-service centers to have a proportion of minorities that equals or exceeds the proportion of minorities that reside in their service areas.

- ***The distribution of minority donors is concentrated in a few donor centers. As of October 1995, 12 of the 97 donor centers account for more than 50 percent of all donors from minority groups.***

These same 12 centers accounted for 42 percent of all donors on the registry. Eight of these donor centers are large, with donor lists of over 20,000. The other four have smaller lists

but are in areas of the country with high numbers of minority populations.

Our analysis of these 12 centers showed significant differences between these 12 centers and other 76 centers responding to our survey in two areas: use of minority staff and use of bilingual staff. According to self-reported survey data, all 12 of these centers employ minority staff (vs. 45 of the other 76 donor centers). In 11 of the 12 centers, staff and volunteers speak a second language (vs. 24 out of the other 76 donor centers).

- ***Despite the attention being given to recruitment of donors from minority groups, the NMDP does not have in place performance indicators to measure individual donor centers' progress in recruiting minorities.***

The NMDP has developed nine Continuous Process Improvement (CPI) indicators in five areas to measure the performance of its donor centers. The CPI indicators monitor how quickly donor centers register new donors and how effective donor centers are at retaining donors. Staff at the NMDP told us that the indicators are designed to measure only those variables that a donor center can control. Given the attention on minority recruitment, we find striking the absence of a CPI indicator measuring any aspect of minority recruitment.

DONOR CENTERS RESPONDING TO OUR SURVEY IDENTIFIED THREE MAJOR OBSTACLES TO RECRUITMENT OF MINORITIES TO THE NATIONAL REGISTRY:

- ***Lack of awareness of marrow donation among minorities***

In their survey responses, 98 percent of the donor centers and all 11 recruitment groups called lack of awareness of marrow donation among minorities an obstacle. On our site visits to donor centers and recruitment groups, staff told us that bone marrow donation tends to receive less attention from the leadership in minority communities than in white communities. One possible explanation for the lack of awareness among minorities may be that they see little applicability to their lives, or to the lives of minority patients because minority patients have received a smaller share of bone marrow transplants.

In addition, patients from minority groups are less likely to have success as they progress through the process from initiating a preliminary search for a donor to actual transplantation. Black patients, for example, initiated 8 percent of preliminary searches, but received only 3 percent of transplants. Table 3 (following page) depicts the percentage of known ethnic and racial groups who initiated preliminary searches and who received transplants from the beginning of the NMDP program in December 1987 through October 1995.

Table 3
NUMBER OF SEARCHES AND TRANSPLANTS FOR PATIENTS FROM ALL RACIAL AND ETHNIC GROUPS FROM DECEMBER 1987 THROUGH OCTOBER 1995

Ethnic and Racial Group	Preliminary Searches	Percent of Preliminary Searches*	Number of Transplants	Percent of transplants*
White	18,265	83%	3,259	91%
Hispanic	1,422	6%	169	5%
Black	1,675	8%	104	3%
Asian/Pacific Islander	654	3%	49	1%
American Indian/Alaska Native	104	< 1%	19	< 1%
Other, unknown	3,139	*	275	*
Totals:	25,259		3,875	

* Searches and transplants for patients whose race is unknown are excluded from these percentages, which are calculated on denominators of 22,120 for preliminary searches and 3,600 for transplants.

Source: NMDP Registry Statistics for October 1995.
Analysis: Office of Inspector General (OIG).
Note: These data include searches and transplants for all donor centers, both foreign and domestic.

- ***Mistrust of marrow donation among minority groups***

In their survey responses, 94 percent of the donor centers and 10 out of 11 recruitment groups called mistrust of marrow donation among minority groups an obstacle. For example, donor center and recruitment group staff told us during site visits that mistrust of Western medicine can be a problem in Asian communities. Their resistance stems from a fear of strangers, and in particular fear of doctors. Another issue donor centers confront is distrust of the medical establishment. The donor centers we spoke with told us that they try to reach out to minority groups; however, access to minority establishments (*e.g.*, churches, fraternal organizations, or cultural centers) can be a problem if donor center staff do not have a personal link to a particular establishment.

- ***Language and/or cultural barriers***

Eighty-six percent of donor centers and 10 out of 11 recruitment groups called language and/or cultural barriers an obstacle. Specific examples of cultural and language barriers we learned about during our site visits include:

- The Vietnamese believe that spinal cord contains vital life fluids. If the fluid is removed, a person may become crippled or unable to bear children.

- While 36 donor centers reported in the survey that they employ bilingual staff and volunteers, we were told that it is difficult to find people fluent enough in both languages to explain complex medical terms.

THE NMDP HAS DEVELOPED STRATEGIES TO OVERCOME THESE OBSTACLES. EACH OF THESE STRATEGIES, HOWEVER, CONTAINS SOME VULNERABILITIES THAT MAY LIMIT THEIR EFFECTIVENESS.

- ***NMDP Publications.*** ***Eighty-six of the 88 donor centers responding to our survey report that they are using materials prepared by NMDP to increase awareness and decrease mistrust about marrow donation among minorities.***

The NMDP has developed a variety of promotional materials, including pamphlets, posters and videos. Most of these items are customized for different ethnic and minority communities.

In addition to the NMDP materials, 34 (39 percent) of the donor centers reported developing their own educational materials specifically for minority donors. Thirty-six (41 percent) of the donor centers reported using educational materials developed by other donor centers for minority donors.

- *However, during our site visits, donor center and recruitment group staff raised concerns about these materials' sensitivity to local conditions and, in some cases, the accuracy of translation.*

The staff members we spoke with on our site visits pointed out that a recruitment strategy changes with the target market. Subtle differences, such as whether the donor lives on the east or west coast, can effect the donor center's or recruitment group's marketing strategy. Staff told us that although they find NMDP materials useful, the generic materials are less effective than ones that are tailored to local needs and concerns.

We also heard that materials originating from NMDP headquarters can be inaccurate. Staff at one recruitment group pointed to a brochure in Vietnamese that had more than 20 mistakes.

- ***Recruitment Groups.*** ***Thirty-nine of the 88 donor centers responding to our survey reported that they work with NMDP-accredited recruitment groups as one way of overcoming language and cultural barriers. Seventeen centers reported that they rely on these recruitment groups for more than half of their minority recruitment.***

The NMDP sponsors 11 recruitment groups to help recruit minority donors.[13] To date, these 11 recruitment groups have recruited 60,657 new donors, or slightly less than 4 percent of the NMDP registry. Of these 11 groups, 1 focuses on Hispanic donors; 3 on Asian/Pacific Islander donors; 2 on black donors; the rest are general in their orientation.

The 39 donor centers that work with recruitment groups reported mixed experiences. Staff at some donor centers responded with statements such as "recruitment groups effectively

bridge the cultural gap." Staff at other donor centers told us that "we work better without them" and that "it requires too much work to jointly handle a drive." Throughout our site visits it became apparent that for donor centers with on-going relationships with recruitment groups, the experience could be positive, resulting in increased access to minority communities. However, it also became apparent that many donor center and recruitment group staff were unclear on exactly how to work together. Typically contentious issues include who should monitor drives and how should fees be split.

Importantly, the reimbursement system appears to have a significant effect on the extent to which donor centers hold drives together. The 62 donor centers reimbursed by NMDP on a fee-for-service basis receive a fixed amount for each donor they recruit ($10 for each white, $28 for each person from a racial or ethnic minority). Because these recruitment fees are the financial base of any fee-for-service donor center, the incentive to be the sole sponsor of a drive is very strong. Sharing recruitment fees has a direct, negative impact on any of these donor centers' bottom line.

- *Despite turning to recruitment groups to play a major role in recruiting minority donors, NMDP does not have in place performance indicators to measure their ongoing effectiveness.*

The performance of NMDP donor centers is assessed every month using CPI indicators. Because no comparable indicators exist for recruitment groups, the NMDP has no on-going way to measure their activities. Just as donor centers must be measured on aspects they can control, the recruitment groups feel that the same policy should hold if CPI-type indicators are instituted.

Some donor center staff told us that the current system of performance measurement unfairly penalizes donor centers that work with unreliable recruitment groups. Once the donor is handed over to the donor center, that donor's performance becomes part of the donor center's CPI indicators. One donor center we visited had a fairly large donor list, a fifth of which came from a now-extinct recruitment group. When they first acquired donors from that group their CPI indicators showed that as many as 70 percent of their donors failed to come forward for followup testing.

RECOMMENDATIONS

Since its inception in 1987, the National Marrow Donor Program (NMDP) has come a long way in increasing the proportion of minority donors on the registry. Minority donors accounted for about 6 percent of the registry in December 1989.[14] Today, minority donors represent 25 percent of the donors on the registry.

However, our findings from this report show that the NMDP needs to continue and build upon the progress made to date in recruiting--and retaining--donors from racial and ethnic minority groups. We raise these concerns because the current racial and ethnic distribution of the registry does not appear to meet the requirements of the Transplant Act: that a patient in a minority group have a comparable chance of finding an unrelated donor as a patient who is not in a minority group.

We developed our recommendations to encourage 1) further improvement in minority recruitment and 2) the development of performance indicators for monitoring minority recruitment. We believe that effectively carrying out our recommendations will require a partnership approach between HRSA and NMDP, and between NMDP and its donor centers. Consequently, we direct our recommendations to both HRSA, in its role as contractor for the registry, and to NMDP, as the holder of that contract.

PERFORMANCE INDICATORS FOR DONOR CENTERS. **In the next contract, the Health Resources and Services Administration should require that the National Marrow Donor Program develop and implement performance indicators that measure the progress of individual donors centers in recruiting donors from racial and ethnic minority groups.** We urge that these performance indicators be implemented within the first year of the new contract. Donor centers falling short on these indicators should be subject to disciplinary actions, up to and including withdrawal of their participation agreement with the NMDP.

We offer the following options as indicative of approaches that might be considered. We encourage HRSA and the contractor to develop additional ideas to implement our recommendation of establishing minority recruitment goals as a way to improve access to transplantation for members of racial and ethnic minority groups.

- A reasonable beginning expectation would be that the proportion of minority donors on a center's list must reflect, at a minimum, the proportion of minority donors residing in its service area.

- The HRSA and NMDP could choose to be more aggressive and give additional impetus to minority recruitment by requiring that a donor center's list must exceed by some factor the proportion of minority donors in the local service area.

- An alternative approach would require that donor centers recruit some specified percentage of the minority populations living in their service area. Rather than peg that percentage to the donor center's list, as our previous option does, this approach

would, in effect, set a target number of donors from minority groups. That target number would be based on the number of minority residents living in the center's service area.

PERFORMANCE INDICATORS FOR RECRUITMENT GROUPS. **In the next contract, the Health Resources and Services Administration should require that the National Marrow Donor Program develop and implement performance indicators that measure the accomplishments of recruitment groups.** We urge that these performance indicators be implemented within the first year of the new contract. Recruitment groups falling short on these indicators should be subject to disciplinary actions, up to and including withdrawal of their participation agreement with the NMDP.

Just as the NMDP measures donor centers on aspects they can control, the recruitment groups should also be measured on aspects of the recruitment process that they can control. Possible performance indicators for recruitment groups include:

- Tracking the percentage of donors recruited by each recruitment group that are retained at subsequent attempts to contact them in the donation process.

- Measuring the time it takes each recruitment group to return consent forms to the appropriate donor center.

- Monitoring the number of forms that are properly filled out by each recruitment group.

CONTINGENCY PLANS. **The HRSA should identify steps to be taken should the NMDP continue to fall short on the recruitment goals specified in its current contract, as occurred in the first year among Hispanics.** We urge the NMDP to continue with its plans for a campaign focused on Hispanic donors. If performance indicators for recruitment groups show that they are indeed an effective recruitment source, the HRSA and NMDP might want to consider accrediting and/or funding more groups focusing solely on Hispanic donors. We also encourage HRSA to consider specifying recruitment goals in the contract for American Indians/Alaska Natives.

SHARING EFFECTIVE PRACTICES. **The NMDP should draw on the expertise of those donor centers and recruitment groups that have shown success in minority recruitment as one way of providing assistance to other donor centers in their minority recruitment efforts.** These donor centers and recruitment groups could assist the NMDP in planning and executing national campaigns, in providing contacts to national minority organizations, and in creating, editing, and pretesting foreign language educational materials. The NMDP could also draw on their expertise in designing cultural competency training, improving bilingual capacity, developing family education strategies, and managing multiracial drives.

COMMENTS ON THE DRAFT REPORT

We sought comments on the draft report from the Health Resources and Services Administration (HRSA), the Assistant Secretary for Planning and Evaluation (ASPE), and the Assistant Secretary for Health (ASH). In addition, HRSA requested comments on the report from the National Marrow Donor Program (NMDP).

HRSA concurs with our recommendations, with the exception that the agency believes that it is not possible to implement performance indicators before signing the next contract. HRSA expects to issue the request for contract to operate the registry in December 1996, with a contract award expected by April 30, 1997. Our goal in recommending the adoption of performance indicators prior to awarding the next contract was to convey the urgency with which this issue needs to be addressed. We strongly urge HRSA and the NMDP to move with utmost speed to develop such indicators, as a way of increasing the chance for donors from racial and ethnic minority groups to find matching donors.

Although these performance indicators will not be in place prior to awarding the contract, we are pleased that the contract will require "specific information about the development and implementation of the plan [for the development of performance indicators] with appropriate due dates and disciplinary actions. . . The request for contract for the next contract period will require that performance indicators and disciplinary actions be developed and that agreements with" donor centers be modified to include the performance indicators and disciplinary actions that will be taken if the center fails to meet the indicators. Accordingly, we modify the language of the recommendation from our draft report to reflect HRSA's concerns. We add language in our recommendation urging that the indicators be implemented within the first year of the new contract. We believe that such a time frame is adequate to achieve these changes.

We add time lines because we are concerned that an open-ended time frame could result in unnecessary delays. We wish to go on record as stating clearly that developing, implementing, and enforcing performance standards for recruitment of donors from minority groups are important, and need to be accomplished as quickly as possible.

We fully agree that individual donor center goals should be based upon the minority population in the area served by the donor center. In our draft report, we listed three options that were indicative of approaches that might be considered. We continue to list those options in this final report, but we also add language encouraging HRSA and the contractor to develop additional ideas to implement our recommendation to establish overall minority recruitment goals as a way of improving access to transplantation for minority patients. We have no objection to numerical performance indicators over percentages.

HRSA agrees that performance indicators for recruitment groups should be in place, but notes that there is not enough time to develop these prior to awarding the next contract. We therefore are changing our recommendation to reflect HRSA's concerns. We add language in our recommendation urging that the indicators be implemented within the first year of the

new contract.

HRSA agrees with our other two recommendations--to develop contingency plans for cases in which recruitment falls short of goals, and to share effective practices.

NMDP's comments were similar to HRSA's. We do, however, wish to address one point in particular, NMDP's comments on goals for recruitment of donors from minority groups. We agree that recruitment of minorities should be a significant segment in evaluating the effectiveness of a donor center. We do not, however, agree with the NMDP's caveat that this should only be a criteria in an area where "it makes sense to recruit a given minority." In our view, *all* donor centers have a role to play in improving the chances for minority patients awaiting transplant to find a donor. For this reason, we continue to recommend some type of linkage between recruitment goals and the minority population in each donor center's service area.

The Assistant Secretary for Health comments that the recommendations contained in this report are important and should be implemented as quickly as possible. ASH also comments that cultural competency training and bilingual capability be included in the HRSA contract, and that educational materials be pretested with a sample of the target population prior to their use. Although we do not include these items as separate recommendations, we do add them as topics to be included in sharing effective practices.

ASH raises other points upon which we wish to comment. Determining why whites constitute 91 percent of transplants but only 83 percent of preliminary searches--and, conversely, why members of minority groups constitute 18 percent of preliminary searches but only 9 percent of transplants--was outside the scope of our study. It is, of course, possible to hypothesize a number of factors, including antigen matching and financial barriers, that may limit access to transplants among members of minority groups. Even though, as ASH notes, Asian/Pacific Islanders on the donor list represent a larger proportion of donors than in the general population, they had received only one percent of the transplants through October 1995. Finally, ASH questions why the HRSA contract does not include recruitment goals for American Indian/Alaska Native populations, as it does for other members of minority groups; we would have no objection to HRSA's adding goals for this group within the forthcoming contract.

ASPE had no comments on this report.

APPENDIX A

SELECTED FINDINGS FROM THE MAIL SURVEYS

From the donor center surveys:

We would like your assessment of the relative importance of the following obstacles to ***minority recruitment*** in the area you serve. Please indicate the degree to which you believe these to be obstacles. If you feel that an obstacle not listed here is important, please write it in the space provided.

Potential obstacles to recruitment of minority donors	Not an Obstacle	Minor Obstacle	Major Obstacle
Lack of awareness of marrow donation among minorities	1 (1%)	16 (18%)	70 (80%)
Lack of good educational materials targeted toward minorities	40 (46%)	31 (36%)	16 (18%)
Language and/or cultural barriers	12 (14%)	38 (44%)	37 (42%)
Mistrust of marrow donation among minority groups	5 (6%)	24 (27%)	58 (67%)
Lack of dedicated staff for minority recruitment	42 (48%)	22 (25%)	23 (26%)
Lack of volunteer support for minority recruitment	32 (37%)	36 (41%)	19 (22%)
Small minority population in the service area	50 (57%)	19 (22%)	18 (21%)

Note: N=87 responses

Does your donor center employ any of the following strategies to increase *minority recruitment*?	Yes	No
Donor center staff speak 2nd language	35 (40%)	53 (60%)
Donor center employs minority staff	57 (65%)	31 (35%)
Donor center works with recruitment groups	49 (56%)	39 (44%)
Donor center works with minority organizations or institutions	83 (94%)	5 (6%)
Donor center sponsors drives targeted specifically at minority groups	82 (93%)	6 (7%)
Donor center uses educational materials designed by NMDP specifically for minority donors	86 (98%)	2 (2%)
Donor center has developed its own educational materials specifically for minority donors	34 (39%)	54 (61%)
Donor center uses educational materials developed by other donor centers for minority donors	36 (41%)	52 (59%)

Note: N=88 responses

	Yes	No
Did your donor center work with any **NMDP accredited recruitment groups** between July 1, 1994 and June 30, 1995? ***(If you answered "yes," please answer the rest of the questions on this page; if you answered "no" please go to the next page.)***	39 (44%)	49 (56%)

Note: N=88 responses

The following questions pertain to the 39 donor centers working with NMDP accredited recruitment groups:

Please check one statement for general recruitment and one statement for minority recruitment to show how much your donor center worked with ***NMDP accredited recruitment groups*** over the past year.	General Recruitment	Minority Recruitment
We relied on them for well over half of our recruitment	8 (20%)	--
We relied on them for about half of our recruitment	9 (22%)	3 (9%)
We rarely worked with them	19 (51%)	11 (29%)
We never worked with them	3 (7%)	25 (63%)

Note: N=39 responses

In your experience, how do donors recruited by ***NMDP accredited recruitment groups*** compare with donors recruited by your center in each of the following areas?	Donor Center Recruits are More Available	No Difference Between the Two	Recruitment Group Recruits are More Available	Not Enough Experience to Judge
Donor availability at DR-typing	15 (39%)	11 (29%)	1 (2%)	11 (29%)
Donor availability at confirmatory testing	14 (37%)	9 (22%)	1 (2%)	15 (39%)
Actual donation/marrow collection	8 (20%)	11 (27%)	1 (2%)	19 (51%)

Note: N=39 responses

From the recruitment group surveys:

We would like your assessment of the relative importance of the following obstacles to ***minority recruitment*** in the area you serve. Please indicate the degree to which you believe these to be obstacles. If you feel that an obstacle not listed here is important, please write it in the space provided.

Potential obstacles to recruitment of minority donors	Not an Obstacle	Minor Obstacle	Major Obstacle
Lack of awareness of marrow donation among minorities	--	--	11
Lack of good educational materials targeted toward minorities	4	5	2
Language and/or cultural barriers	1	5	5
Mistrust of marrow donation among minority groups	1	3	7
Lack of dedicated staff for minority recruitment	5	3	3
Lack of volunteer support for minority recruitment	3	5	3
Small minority population in the service area	8	2	1

Note: N=11 responses

Does your recruitment group employ any of the following strategies to increase ***minority recruitment?***	Yes	No
Recruitment group staff speak 2nd language	7	4
Recruitment group employs minority staff	8	2
Recruitment group works with recruitment groups	8	3
Recruitment group works with minority organizations or institutions	11	--
Recruitment group sponsors drives targeted specifically at minority groups	11	--
Recruitment group uses educational materials designed by NMDP specifically for minority donors	11	--
Recruitment group has developed its own educational materials specifically for minority donors	7	3
Recruitment group uses educational materials developed by other donor centers for minority donors	3	7

Note: N=11 responses

APPENDIX B

METHODOLOGY

Data Analysis

The quantitative portions of this report are based on three sources: (1) Registry data maintained by the NMDP; (2) NMDP's "Donor Center Access Directory" for October, 1995; and (3) 1990 U.S. Census data.

(1) We examined monthly summary statistics from the NMDP, from April 1993 through October 1995. These reports contain a center-by-center breakdown of the number of donors on the Registry by five racial and ethnic groups: Black, white, Hispanic, Asian/Pacific Islander, and American Indian/Alaska Native. (2) We used the NMDP's "Donor Center Service Access Directory" to identify the service area of each donor center at the county level. (3) We used county level population data from the 1990 U.S. Census to determine the population distribution by racial and ethnic group of each donor center's service area.

We used data bases constructed in Lotus 1-2-3 to compare the racial and ethnic distribution of each center's donor list as of October 1995 with the 1990 Census population distribution.

The number of donor centers on the NMDP Registry is in a continual state of flux, with centers merging and others being added. For comparative purposes, we used a denominator of 97 donor centers. Where centers have merged we combined appropriate data files. Where we analyzed geographic service areas, we omitted the Bill Young Marrow Donor Center because it contains military donors throughout the world. In such cases, the base-line denominator was reduced to 96.

Mail Surveys of Donor Centers and Recruitment Groups

In July 1995 we mailed a pre-tested survey to each of the 98 donor centers then in operation and to all 11 recruitment groups. We received surveys from 88 of the donor centers and all 11 recruitment groups. Because one of the donor centers has since merged with another center, we chose to omit the responses of that center from our analysis.

The donor center survey addressed four areas of donor center operations: donor center staff and activities; donor recruitment; search and work-up activities; and financial information. The recruitment group survey addressed recruitment group staffing and donor recruitment. This report draws on material from the second and third sections of the donor center survey and the recruitment group survey. A non-respondent analysis showed no difference among those donor centers that participated and those that did not.

Site Visits to Donor Centers and Recruitment Groups

We conducted site visits with staff at nine donors centers and four recruitment groups. We

chose a judgmental sample of donor centers and recruitment groups that were geographically diverse; varied in size and composition of the donor lists; funded on both contract and fee bases; and located in a variety of settings, including free-standing centers, blood banks and hospitals. Using an open-ended questions we interviewed staff about barriers and strategies to minority recruitment, performance indicators, and use of recruitment groups.

APPENDIX C

TEXT OF COMMENTS ON THE DRAFT REPORT

Note: The Health Resources and Services Administration and the National Marrow Donor Program provide combined comments on four draft reports that examined the National Marrow Donor Program. This appendix includes only those portions of their comments that are relevant to the report entitled "National Marrow Donor Program: Progress in Minority Recruitment."

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Health Resources and
Services Administration
Rockville MD 20857

OCT 23 1996

TO: Inspector General, DHHS

FROM: Deputy Administrator

SUBJECT: Office of Inspector General (OIG) Draft Reports, "National Marrow Donor Program (NMDP):
1) Financing Donor Centers OEI-01-95-00123
2) Progress in Minority Recruitment OEI-01-95-00120
3) Geographic Overlap Among Donor Centers OEI-01-95-00122
4) Effectiveness in Retaining Donors OEI-01-95-00121"

Attached is HRSA's response to your memorandum requesting comments on the four subject draft reports.

We appreciate the OIG conducting the review, "Bone Marrow Program Inspection." The draft reports were forwarded to the NMDP for comment. Their comments have been incorporated into our response. HRSA and NMDP will be performing further analysis and examination regarding some issues, such as restructuring of donor centers, implementation of performance indicators, and specification of retention rates, before specific changes are made. HRSA plans to utilize the findings and recommendations contained in these reports as an integral part of the development of the contract.

Questions may be referred to Deirdre Walsh on x35181.

John D. Mahoney

Attachment

OIG Report: Progress in Minority Recruitment OEI-01-95-00120

GENERAL COMMENTS

The concerns raised in this report warrant careful consideration. HRSA agrees that the contractor needs to continue to expand recruitment and retention of donors from racial and ethnic minority groups because the current racial and ethnic distribution of the registry does not appear to provide a member of a racial/ethnic minority an equal chance of finding an unrelated donor as a patient who is not in a minority group.

OIG RECOMMENDATION:

PERFORMANCE INDICATORS FOR DONOR CENTERS. The Health Resources and Services Administration, prior to awarding any future contract for the registry, should require that the National Marrow Donor Program have in place a performance indicator that measures the progress of individual donor centers in recruiting donors from each of the four racial and ethnic groups. Donor centers falling short on this indicator should be subject to disciplinary actions, up to and including withdrawal of their participation agreement with the NMDP.

HRSA RESPONSE

HRSA does concur with the recommendation that the contractor have in place a performance indicator that measures the progress of individual donor centers in recruiting donors from each of the four racial and ethnic groups. However, HRSA does not concur that a performance indicator should be required prior to awarding any future contract for the registry. The current contract expires April 30, 1997 and there is not sufficient time to adequately develop performance indicators and implement plans for disciplinary actions.

HRSA agrees that the contractor needs to develop and implement performance indicators with respect to minority recruitment and be held accountable for achieving the performance standards. The OIG has provided some alternative approaches, implying that the performance measures will need careful consideration. It is doubtful that performance indicators and disciplinary actions can be implemented with appropriate care prior to awarding the next HRSA contract.

Developing performance indicators for the individual donor centers and implementation plans could not be completed prior to the award of the next contract. NMDP has contracts and sub-contracts with the donor centers and these would need to be modified to fully implement a plan. The target date for the Request for Proposal is December, 1996 with the award by April

30, 1997. These dates provide insufficient time for the contractor to develop a performance indicator and implementation plan for individual donor centers with input from the donor centers.

However, HRSA concurs that having a performance indicator for minority recruitment is a worthwhile activity. HRSA will require a plan for the development of performance indicators and implementation plans. Specific information about the development and implementation of the plan with appropriate due dates and disciplinary actions should be included in the next contract. The request for contract for the next contract period will require that performance indicators and disciplinary actions be developed and that agreements with donor centers be modified to include the performance indicators and disciplinary actions.

Therefore, HRSA suggests the following modification:

> HRSA should require that performance indicators and implementation plans with appropriate due dates be included in the next contract.

HRSA does agree that the contractor needs to continue to recruit and retain donors from racial and ethnic minority groups because the current demographic distribution of the registry does not provide a member of a racial/ethnic minority an equal chance of finding an unrelated donor as a patient who is not in a minority group.

HRSA and the contractor should evaluate the alternative approaches and reach consensus with donor centers. For example, the contractor could require that a donor center's list must exceed by some factor the proportion of minority donors in the local service area. An alternative approach, requiring that a donor center recruit some specified percentage of the minority populations living in the service area, is a preferable approach because it allows for the contractor to target a specified number of donors (or percentage) from the populations in the area and would allow more flexibility.

By targeting the percentage of the population that resides in the service area, HRSA would not be taking into account large family drives that force down the percentage of minorities in a file. The most important consideration is <u>improving</u> the likelihood for a minority patient to find a donor and <u>increasing</u> the percentage of new donors from minority groups. Percentages are not necessarily relevant.

Expressing minority recruitment goals as a percentage of the population may be subject to misinterpretation. A target <u>number</u> of new donors from each minority group for each donor center

would be a more useful measure.

A modified recommendation would stress that overall minority recruitment goals should aim at providing improved access for minority patients. Individual donor center goals should be based upon the minority population in that area.

OIG RECOMMENDATION:

PERFORMANCE INDICATORS FOR RECRUITMENT GROUPS. HRSA, prior to awarding any future contract for the registry, should require that NMDP have in place performance indicators that measure accomplishments of recruitment groups.

HRSA RESPONSE:

HRSA agrees that the contractor should have in place performance indicators for recruitment groups, but this recommendation does not allow time for the development or the implementation of these performance indicators. Developing the indicators, disciplinary actions, and modifications of contractual agreements with recruitment groups will require more time than is available prior to the award of the contract. HRSA expects that the Request for Proposal for the next contract will require that agreements with recruitment groups be modified to develop or include specific performance indicators, implementation plans, and disciplinary actions.

The alternatives offered are operational and will be considered as performance indicators are developed. The NMDP has made initial recommendations to employ forms monitoring and timeliness of consent forms submission as measures of recruitment group performance and would improve efficiency in minority recruitment.

HRSA recommends the following modification:

> HRSA should work with the contractor to develop performance indicators and implementation plans for recruitment groups .

OIG RECOMMENDATION:

CONTINGENCY PLANS. HRSA should identify steps to be taken should the NMDP continue to fall short on the recruitment goals specified in its current contract, as occurred in the first year among Hispanics.

HRSA RESPONSE:

HRSA agrees with this recommendation. HRSA expects that the next RFP will include a requirement that the contractor submit a report at least annually on recruitment group activities with a

determination of whether recruitment goals for minority groups are being met and whether any shortfall is permanent or temporary. The report will include recruitment group specific information about goals and achievements and allocations of staff time for minority versus Caucasian recruitment. The proposal will specify a corrective action plan for recruitment groups that are deficient on recruitment goals and will require the contractor (currently NMDP) to be responsible for developing and implementing these performance goals.

OIG RECOMMENDATION:

SHARING EFFECTIVE PRACTICES. The NMDP should draw on the expertise of those donor centers and recruitment groups that have shown success in minority recruitment as one way of providing assistance to other donor centers in their minority recruitment efforts.

HRSA RESPONSE:

HRSA supports the recommendation that the contractor should undertake demonstration projects aimed at increasing the retention rate among minority donors. We agree that the contractor should make better use of the expertise of donor centers and recruitment groups that have had success in recruiting donors.

HRSA agrees that recruitment of minorities should be a significant factor in the evaluation of the effectiveness of a donor center, particularly in areas with high numbers of minorities. HRSA agrees that Continuous Process Improvement monitoring should be an important part of the evaluation process. HRSA agrees that the next Request for Proposal will require a plan to identify and conduct projects to demonstrate the effectiveness of specific innovative strategies for improving retention and effectiveness.

NMDP has included workshops at its annual Council meeting to address retention of donors. The 1996 Council meeting included two workshops on "Planning for a Long Registry Life: Donor Retention"and several activities related to special initiatives for minority groups, including recognition of the Asian/Pacific Islander and the African Americans United for Life campaigns, the minority initiatives (Hispanic, African American, American Indian/Alaskan Native, and Asian/Pacific Islander). These workshops featured representatives from donor centers and recruitment groups with expertise and success in improving recruitment and retention among minorities.

The contractor has four standing committees that address donor center and recruitment group activities, particularly with

minorities -- Membership and Process Improvement, Minority Affairs, Donor Recruitment, and Patient Services. These committees include representatives from donor centers, recruitment groups, and minority populations.

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secret

AUG 28 1996

Assistant Secretary for Hea
Office of Public Health and Scien
Washington D.C. 202

TO: Inspector General

FROM: Assistant Secretary for Health

SUBJECT: OIG Draft Reports on the National Marrow Donor Program

Thank you for the opportunity to review the Office of the Inspector General's Draft Reports on the National Marrow Donor Program. I am pleased that in general the reports show that much progress has been made. However, the reports also showed that there are additional areas where the Department must focus its attention. The recommendations contained in these reports are important and should be implemented as quickly as possible.

Attached are several areas which I believe should be addressed in the reports. Thank you for the opportunity to review these important reports. If you have any questions on the concerns raised, please call Mr. Matthew Murguia of the Office of Minority Health at 301-443-9923.

Phillip R. Lee, M.D.

Attachment

OIG DRAFT REPORTS ON THE NATIONAL MARROW DONOR PROGRAM

- **REPORT: Progress in Minority Recruitment**

-- The use of the terms "Caucasian" and "whites" are interchangeably used throughout the report. OIG may consider using the OMB Directive 15 classification for describing the various racial/ethnic groups, which are "white, black, Asian/Pacific Islander, American Indian/Alaska Native, and Hispanic."

-- There should be some discussion as to why the HRSA contract does not specify annual recruitment goals for Native Americans (page 6).

-- There should be some discussion as to why whites constitute 83% of preliminary searches, but account for 91% of transplants (Table 3, page 10).

-- The discussion of mistrust by Asians on page 10 is contradicted by the discussion on page 5 which indicates that Asians are over represented in the donor pool.

-- On page 11, is cultural competency training, including bilingual capability, included in the HRSA contract? If not, this avenue should be explored as a means to find bilingual staff, especially those knowledgeable about medical terms.

-- On page 11, OIG should consider a recommendation which would require a pre-test with a sample of the target population of educational materials prior to their use.

- **REPORT: Effectiveness in Retaining Donors**

-- The use of the terms "Caucasian" and "whites" are interchangeably used throughout the report. OIG may consider using the OMB Directive 15 classification for describing the various racial/ethnic groups, which are "white, black, Asian/Pacific Islander, American Indian/Alaska Native, and Hispanic."

-- Figure 2, page 12, shows that 10 - 17 percent of donor centers indicate that language barriers present an obstacle to search and workup. However, this issue does not appear to be discussed, nor are any recommendations to address this area contained in the report. Given the large percentage of centers reporting this as a problem, and the stated fact that it is more difficult to maintain minority donors, an examination of this issue would be appropriate.

National Marrow
Donor Program

National Coordinating Center
3433 Broadway Street N.E.
Suite 500
Minneapolis, MN 55413
612-627-5800
1-800-526-7809
FAX: 612-627-5899

With funding from:
Health Resources and Services Administration and
Naval Medical Research and Development Command

September 4, 1996

Judith Braslow
Director, Division of Organ Transplantation
Health Resources and Services Administration
Park Lawn Building
5600 Fishers Lane - Room 729
Rockville, MD 20857

Dear Ms. Braslow:

Thank you very much for providing the National Marrow Donor Program® (NMDP) with an opportunity to review the draft reports of the Office of Inspector General (OIG), Department of Health and Human Services. The draft reports were sent to members of the Minority Affairs, Membership and Process Improvement, Donor Recruitment and Executive Committees as well as the NMDP's Network Evaluation Advisory Panel and selected members of the staff.

The comments received have been collated and a synthesis of the responses is presented below. The intent of the NMDP is not to criticize the draft reports, but rather to add information from a variety of respondents, all of whom have been involved with aspects of donor center operations and/or donor recruitment. As you know the NMDP is well along in its own analysis of donor center functions, the findings of which should provide further useful recommendations.

Following the summary of comments on each draft report we have provided our own list of recommendations for modification of the OIG document.

Minority Recruitment

Several issues were raised about this draft report. It was pointed out that expressing minority recruitment goals as a percentage of the population was subject to misinterpretation and that a target number based upon previous experience, while stil subject to error, would be a more useful measure. An example of the problem in usi a percentage of the population guideline is found in the fact that the NMDP's recruitment of Asian-Pacific Islanders (A-PI) already exceeds the percentage of this racial group in the general population and yet the NMDP does not have enough A-PI

to provide A-PI patients equal access to unrelated transplants. A similar comment emphasized that the NMDP is better able to identify donors for Hispanic patients than for African American patients because Hispanics are more likely to match with Caucasian donors. Thus recruitment goals commensurate with providing more equal access for minority patients may be a better basis for this calculation.

Several respondents made reference to the idea that not every donor center should necessarily be expected to be an equally effective minority donor recruiter. It was suggested that resources (and expectations) be disproportionately higher in regions of large minority populations as a possible way to increase cost effectiveness.

There was agreement with the draft report in considering minority recruitment as a part of a center's overall performance. There was also felt to be a need to monitor the effectiveness of recruitment groups since some donor centers rely solely upon these groups to recruit minority donors.

A recruitment group representative felt that the draft report proposals to employ forms monitoring and timeliness of consent forms submission as measures of recruitment group performance were valid and would improve the NMDP's efficiency in minority donor recruitment. There was also support for the recommendation to undertake demonstration projects aimed at increasing the retention rate among minority donors. It was of interest that in the case of this particular recruitment group, work with their donor centers to improve retention was already in progress .

Another point of agreement with the draft report was to repeat several of the analyses in the face of the rapidly increasing recruitment of minority donors and to make better use of "the expertise of those donor centers and recruitment groups that have succeeded in recruiting minority donors."

In considering changes in the methods of financial support for donor centers, a medical director expressed a note of caution: There is a real danger that certain successful models for minority recruitment efforts could be jeopardized by decreased funding.

It is again important to point out an NMDP initiative that is currently in its early stages, but promises to add strategic data and recommendations for minority recruitment: The NMDP's study of optimal registry size. Using available information about the likelihood of finding a successful match for patients of all races and recruitment/retention statistics and projections, a panel of biostatisticians will provide quantitative information about future recruitment requirements.

Recommended Modifications to the Draft Report:

- Minority recruitment goals should not be targeted to the percent in the population served. A-PI recruitment already exceeds the percent in the population, yet we have insufficient A-PI donors to give them an equal chance of finding a compatible donor. Large Caucasian family drives force down the percent of minorities in a file. These are only a few of the arguments. Numerical targets are more meaningful.

- We agree that recruitment of minorities should be a significant segment in our evaluation of the effectiveness of a donor center, provided the center is located in an area where it makes sense to recruit a given minority.

- Continuous process improvement monitoring should be an important part of the evaluation process.

We are already embarked upon continuing the efforts begun with these OIG draft reports. Our own detailed evaluation of costs to recruit donors and retrieve them for donation is well under way. The effects of geographic overlap are being evaluated by our Network Evaluation Advisory Panel and by several committees. Minority recruitment approaches and donor retention are areas of high concern, being addressed by our Minority Affairs Committee, the Donor Recruitment Committee, and the Membership and Process Improvement Committee.

These are all high priority items for our Board of Directors, which will be reviewing these documents at its regular meeting in several weeks.

We hope that you find these comments helpful. The NMDP thanks you for sharing these draft reports and looks forward to a continuing collaboration in improving all aspects of donor center and recruitment group operations.

Yours truly,

Craig W. S. Howe, M.D., Ph.D.
Chief Executive Officer

Herbert A. Perkins, M.D.
NMDP Board Chair

APPENDIX D

ENDNOTES

1. *The Living Gift of Life*, a pamphlet by the National Marrow Donor Program.

2. *Bone Marrow Transplants - A Book of Basics for Patients* (reprinted by NYSERnet, Inc. with permission from BMT newsletter), chapter 4, pp. 35-36.

3. 42 U.S.C.§k(b)(1)-(7)

4. 42 U.S.C.§274k(b)(1)-(7)

5. Table 2 (page 20) and Table 11 (page 38) in *1995 Annual Report of the U.S. Scientific Registry for Transplant Recipients and the Organ Procurement and Transplantation Network, Transplant Data: 1998-1994*, United Network for Organ Sharing, Richmond, VA, and the Division of Transplantation, Bureau of Health Resources Development, Health Resources and Services Administration, U.S. Department of Health and Human Services, Rockville, MD.

6. U.S. General Accounting Office, *Bone Marrow Transplants: National Program Has Greatly Increased Pool of Potential Donors*, GAO/HRD-93-11, November 1992, p.11.

7. Persons of Hispanic origin may be of any race. The NMDP also categorizes donors as Unknown, Decline, or Other. Donors categorized as "others" increased from 34,164 to 36,181. In determining the percentage of minorities on the list, we calculated minorities as a percentage of the total number of donors on the registry. Because we could not ascertain the race or ethnicity of donors listed as Unknown, Decline, or Other, we included them in the denominator but did not assign them to any racial or ethnic group.

8. African Americans Uniting for Life was the first campaign to be launched. The metropolitan areas selected for this campaign included: Atlanta, Baltimore, Chicago, Dallas, Houston, Jacksonville, Kansas, Memphis, New Orleans, Tampa/St. Petersburg, and the District of Columbia. Asian/Pacific Islander Donors Can Save Lives is the title of the NMDP campaign focusing on Asian and Pacific Islander donors. The target markets for this campaign included: Northern and Southern California, New York, Seattle, Hawaii, and Chicago.

9. Target markets for this campaign include: Los Angeles/Orange County, California; southern and eastern Texas; and Puerto Rico.

10. New York City, Los Angeles, Chicago and other cities have alleged that the 1990 U.S. Census undercounts minorities. The U.S. Government has acknowledged that it missed about 1.6 percent of the nation's population, including about 4.8 percent of blacks and 5.2 percent of Hispanics. In March 1996, the Supreme Court has decided that the 1990 census count does not need to be revised.

11. We present here a copy of Table 5 from that report, which presents data on the retention rate by racial and ethnic group:

Table 5
RETENTION RATE AT dr TYPING AND AT ct TESTING
FOR RACIAL AND ETHNIC GROUPS FROM DECEMBER 1987 THROUGH OCTOBER 1995

Ethnic and Racial Group	DR Testing		CT Testing	
	Oct 1, 1992 - Sept 30, 1993	Oct 1, 1994 - Sept 30, 1995	Oct 1, 1992- Sept 30, 1993	Oct 1, 1994- Sept 30, 1995
Caucasian	71 %	76 %	83 %	81 %
Hispanic	56 %	63 %	70 %	62 %
African American	55 %	68 %	70 %	59 %
Asian and Pacific Islander	47 %	62 %	59 %	51 %
Native American	71 %	74 %	69 %	76 %
Totals:	66 %	72 %	81 %	76 %

Source: NMDP Registry Statistics
Analysis: Office of Inspector General (OIG).

12. Because we compared 1995 recruitment levels with population data from the 1990 U.S. census, the true proportion of minority donors in each center's service area may be underestimated. This should be considered a conservative estimate.

13. The NMDP has recently accredited a new recruitment group called SAMAR. This recruitment group targets Asian Indian donors.

14. U.S. General Accounting Office, *Bone Marrow Transplants: National Program Has Greatly Increased Pool of Potential Donors*, GAO/HRD-93-11, November 1992.