

Department of Health and Human Services

**OFFICE OF
INSPECTOR GENERAL**

NATIONAL MARROW DONOR PROGRAM

EFFECTIVENESS IN RETAINING DONORS



**JUNE GIBBS BROWN
Inspector General**

DECEMBER 1996

OEI-01-95-00121

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EXECUTIVE SUMMARY

PURPOSE

To assess the effectiveness of the National Marrow Donor Program in retaining donors for bone marrow transplants between unrelated volunteer individuals.

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, or human leukocyte antigens (HLA), must match as closely as possible.

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). The NMDP accredits donor centers that recruit volunteers to join the registry, which contains almost 1.5 million potential donors in 97 domestic donor centers.

Volunteers who join the registry have their blood typed for the HLA-A and -B antigens. If a patient seeking a transplant matches with a donor's antigens, the donor center contacts that donor for first level followup testing to type the donor's HLA-DR antigens. If these antigens match, the donor may be called for second level confirmatory testing, which may lead to marrow donation and transplantation.

Some potential donors, however, do not proceed to followup testing. The term *retention rate* refers to donor centers' success in keeping donors when they are called for followup testing.

This report is based on data maintained by NMDP; a mail survey of 88 of the 97 domestic donor centers; and site visits to 9 donor centers across the country.

FINDINGS

The overall donor retention rate has remained about the same over the past 3 years. While the retention rate has improved for first level followup testing, it has declined for second level confirmatory testing.

Donor retention at first level testing improved to 73 percent for the year ending September 1995, up from 66 percent for the year ending September 1993.

However, donor retention at confirmatory testing declined to 75 percent for the year ending September 1995, down from 81 percent for the year ending September 1993.

Retention rates among donors from racial and ethnic minority groups lag behind those for whites.

At first level testing, the retention rate for minority donors improved to 66 percent for the year ending September 1995, up from 55 percent for the year ending September 1993. In comparison, the retention rate among white donors grew from 71 percent to 76 percent.

However, retention of minority donors at confirmatory testing declined to 60 percent for the year ending September 1995, down from 67 percent for the year ending September 1993, while it fell from 83 to 81 percent among white donors.

Even though the decrease in donor retention rates at confirmatory testing is small, it still raises some concerns.

The NMDP and donor centers have gained substantial experience in donor registration and education, adopted new technologies for locating donors, and developed continuous process improvement indicators. We had expected ongoing improvement in retention. Although improvement was evident at first level followup testing, we found that this was not the case at confirmatory testing. Our review identified three factors that may explain this trend:

Lack of direct donor commitment at the first level followup stage. Some donors were typed for their HLA-DR antigens at initial registration. Because only verbal permission is required, these donors do not need to be tested again until the confirmatory testing stage. All new minority donors are typed at registration to more readily identify matches. This front end typing may provide one important explanation for the greater decrease in their retention rate at confirmatory testing.

Potential conflict between a rapidly growing registry and donor education. Some donor centers may be emphasizing increases in the number of donors on their list, rather than attracting donors who will come forward when called. Some centers may not be doing an effective job of educating donors at initial recruitment about what will be required of them in the event of a match.

No awareness of decline in confirmatory testing retention rate. Some donor centers may not recognize the decline in donor retention rates at confirmatory testing. Even though donor retention is declining at this stage, donor centers responding to our survey cited obstacles to retention less frequently at confirmatory testing than they did at first level testing.

We raise concerns about the decline in retention at confirmatory testing for two reasons:

Patient expectations are high at confirmatory testing. A request for confirmatory testing occurs when a patient awaiting a transplant knows that a preliminary

potential donor match has been identified. Failing to retain donors at this stage means that the patient's hopes for a transplant may have been raised unrealistically.

Losing donors at confirmatory testing is costly for patients awaiting transplant.

When a patient requests that a potential donor be tested for HLA-DR antigens, that patient is billed an average of \$264. The patient must pay for that test, even if the donor does not come forward at confirmatory testing.

RECOMMENDATIONS

The Health Resources and Services Administration should specify, either upon issuing the forthcoming contract or through a future modification of that contract, the overall retention rate to be achieved by the registry. The current contract specifies goals for recruitment of donors and minority donors, as well as for the number of transplants. However, the contract does not contain goals for retention of donors, the important middle step in that process. We urge HRSA to specify the target retention rate within the first year of the new contract.

To the extent that resources are available, the Health Resources and Services Administration, working with the National Marrow Donor Program, should support demonstration projects that test alternative strategies for retaining donors. We urge that particular attention be paid to demonstrations that seek to increase the retention rate among donors from racial and ethnic minority groups.

The National Marrow Donor Program should work with donor centers to develop and implement methods for improving retention at both the first attempt and subsequent attempts to contact donors. We hope that improving retention among donors from racial and ethnic minority groups will be a focus of these efforts. We encourage NMDP also to put in place plans for evaluating the success of these methods and a strategy for disseminating successful methods to donor centers. Options that might be used to reach that goal include:

Specifying a retention rate in its operating agreement with each donor center.

Augmenting performance indicators to emphasize continuous improvement in donor centers' performance over time.

Enhancing donor education at initial recruitment.

Emphasizing to donor centers the need for full education of donors when contacting them for first level followup testing.

Working with HRSA to devise a strategy for improving publicity around the need for retention and donor maintenance.

COMMENTS ON THE DRAFT REPORT

HRSA and the Assistant Secretary for Health (ASH) provided comments on our draft report, as did NMDP.

The HRSA and NMDP question why we compared changes at first level followup (DR typing) and second level confirmatory (CT) testing, rather than at first attempt and subsequent attempts to contact donors. We agree that it makes sense to think in terms of first attempt at contact and subsequent attempts, as the NMDP and HRSA suggest. However, because NMDP reports data in terms of first level followup testing and confirmatory testing, we continue to use those terms in our analysis. Nevertheless, we have changed our recommendations to encourage overall retention, at both first and subsequent contact attempts.

HRSA agrees with the substance of our recommendation that the contract should specify the retention rate to be achieved, but the agency raises concerns that implementing these recommendations will take longer than we recommended in our draft report. We agree and have changed our recommendation to specify that the appropriate retention rate be implemented through a contract modification, rather than prior to issuing the new contract. We urge that these changes be implemented within the first year of the new contract.

HRSA and NMDP support our recommendation to support demonstration projects that test alternative strategies for retaining donors. We agree that such projects should contain an evaluation component to assess the feasibility of these strategies for broader use. We also urge that these projects pay attention to overcoming language barriers, as recommended by ASH.

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INTRODUCTION

PURPOSE:

To assess the effectiveness of the National Marrow Donor Program in retaining donors for bone marrow transplants between unrelated volunteer individuals.

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 fatal blood diseases.¹ Many 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 finds 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 nonprofit 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 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 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, this time to HRSA in recognition that NMDP was a service delivery program, rather than a basic research initiative.

The major functions of the registry 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." In addition, the statute calls for a system of patient advocacy, support studies and demonstration projects, and the collection and dissemination of data concerning bone marrow transplantation and collection.³

The NMDP accredits 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 hospital departments, 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 Process of Finding a Donor

Finding a donor for bone marrow transplantation involves many steps. Essentially, these steps can be viewed as two basic processes. One is the ongoing process of recruiting and maintaining a pool of potential donors that can be called upon to donate bone marrow. The second process occurs when a patient initiates a search for an unrelated donor from within that pool of potential donors.

Potential donors register with the NMDP through donor centers or recruitment groups. At registration, all donors are typed for their HLA-A and -B antigens.⁴ Because of the high costs associated with their typing and the infrequency with which potential donors are actually called upon to donate, the third pair of antigens, the HLA-DR antigens, traditionally have not been typed until a later stage at the request of a patient needing a transplant.⁵ To protect donors' privacy, information about their HLA type and other demographic and medical information is stored in the NMDP's central computer under a coded system. Only the donor center knows the potential donor's identity.

Any physician can initiate a preliminary search on behalf of a patient at no charge. The preliminary search compares that patient's HLA antigens to the antigens of donors listed in the registry. The NMDP faxes summary information about the number of potential donors in various match-grade categories to the physician within 24 hours of receiving the request. A request for further typing of particular donors (a formal search) must be made through an NMDP-accredited transplant center. The NMDP generates a complete list of each potential donor in order of the best available match.

The patient's physician at the transplant center selects potential donors from the formal search report for further compatibility typing. The physician faxes these requests back to the NMDP coordinating center, which notifies the appropriate donor center that one of its

donors has been selected. The donor center contacts that donor for first level followup testing (DR) to type the donor's HLA-DR antigens. If these antigens match, the patient may be called for second level confirmatory testing (CT).

Eventually, one donor may be identified as the best possible match for the patient. Assuming that this donor is still willing to donate marrow, further typing, testing, work-up, and informed consent take place.⁶ That donor will go to a collection center, where marrow is collected in a surgical procedure. The marrow is then hand delivered to the transplant center where it is infused into the patient's blood system.

Some potential donors, however, do not proceed to followup testing at DR or CT, even if they are a potential match. Yet this is a critical point at which the success of the registry and of individual donor centers needs to be assessed. Their effectiveness in finding donors at these two points directly impacts the success of the program. We use the term retention rate to refer to donor centers' success in keeping donors when they are called for followup testing.

SCOPE and METHODOLOGY

This report addresses the domestic donor centers only. The report is one of four companion reports addressing the National Marrow Donor Program. The other three reports are: *National Marrow Donor Program: Progress in Minority Recruitment* (OEI-01-95-00120); *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 utilizes three primary data sources:

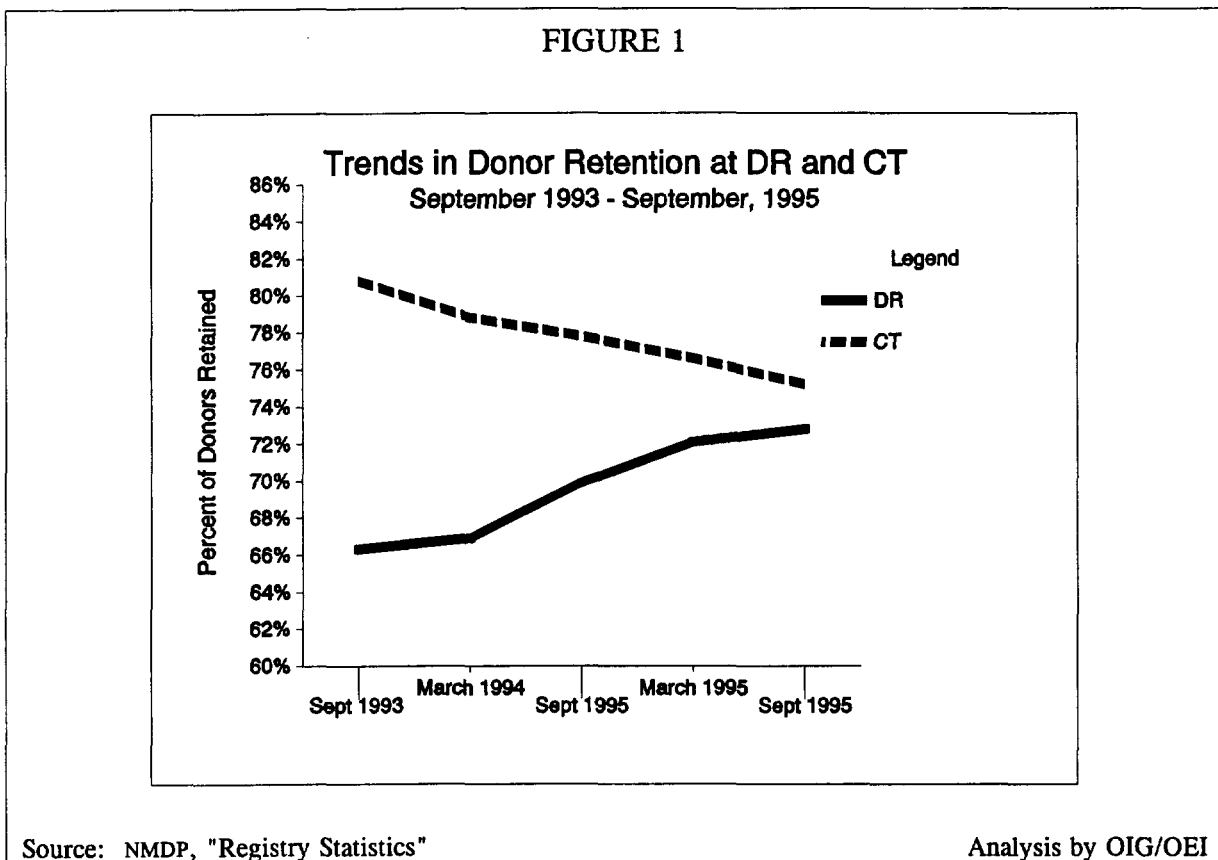
- 1) The NMDP's aggregate statistical data on donor retention at DR typing and CT testing, broken down by donor center. We examined data at the following intervals: two 12-month periods (October 1, 1992 to September 30, 1993 and April 1, 1993 through March 31, 1994) and three 6-month periods (April 1, 1994 through September 30, 1994; October 1, 1994 through March 31, 1995; and April 1, 1995 through September 30, 1995).
- 2) A mail survey of the 97 domestic donor centers. We received 88 responses, a response rate of 91 percent.
- 3) Site visits to donor centers in California, Massachusetts, Minnesota, New Jersey, North Carolina, and South Carolina.

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

FINDINGS

THE OVERALL DONOR RETENTION RATE HAS REMAINED ABOUT THE SAME OVER THE PAST 3 YEARS. WHILE THE RETENTION RATE HAS IMPROVED FOR FIRST LEVEL FOLLOWUP TESTING (DR TESTING), IT HAS DECLINED FOR SECOND LEVEL CONFIRMATORY TESTING.

Figure 1 depicts the trend in donor retention at DR and CT testing at intervals between September 1993 and September 1995.



The NMDP identifies four reasons that an individual may not come forward for further testing at either DR or CT:

- *Unable to contact.* The donor center was unable to contact the donor. For example, the donor may have moved and left no forwarding address.
- *Not Interested.* The donor no longer wishes to be considered as a marrow donor.
- *Medical deferment.* Because donation requires a surgical procedure, donors with certain medical conditions are disqualified.

- *Temporarily unavailable.* The donor is interested and medically appropriate, but his or her schedule is incompatible with the required time frame. For example, the donor may be travelling outside the country, or may be unable to take time off from work to come to the donor center for testing.

The NMDP removes donors who are classified as *unable to contact* or *not interested* from the active registry; they will no longer appear as a potential match in the future. In some cases, donors with *medical deferrals* would be removed from the list (*e.g.*, a permanent condition that renders the person inappropriate for donation), although in other cases (*e.g.*, pregnancy) the donor might appear for future matches. Those who are *temporarily unavailable* remain on the list.

Donor centers and NMDP have put substantial effort into improving how they maintain their donor lists. Donor centers use three strategies to help keep their lists up to date:

Annual Newsletter

Eighty-three of 86 centers responding to our survey told us that they use the NMDP newsletter to update their lists, while 13 of 84 centers told us that they use their own newsletter, either independently or in conjunction with the NMDP newsletter. Fifty-one centers rated the newsletter as their most successful strategy for updating donor lists. The NMDP works with an independent mailing house to send an annual newsletter to all donors. The newsletters use the donor centers' return addresses, rather than the NMDP's. When newsletters are returned as undeliverable, centers flag those donors. At that point these centers try to contact donors using the contact list that the donor provided when signing up as a donor. Some centers put substantial effort into this activity as a way of updating their lists; other centers we spoke with, however, believe that it is more cost effective to put their resources into tracking down donors once they have been identified as potential matches, rather than merely keeping lists up to date.

Donor Identification Cards

In our survey, 69 of 86 centers reported that they give donors a donor identification card prepared by NMDP, while 13 centers issue their own donor identification card. Seven centers rated the donor identification card as the most successful strategy for updating donor lists. The donor identification card serves as an ongoing reminder of the individual's participation in the program. It also encourages donors to call their center with a change of address whenever they move.

Trans Union Credit Service

Trans Union, a computerized reporting service, has been available to donor centers for over 2 years. Three centers rated this as the most effective strategy for updating their lists. The NMDP encourages donor centers to use this service, which we were told cost \$1.25 per search. The donor center logs into a computer system, enters the donor's last

known address or social security number, and the system tracks that person through credit card or other activities.⁷

Donor centers vary in the approaches they take to finding donors and the priority they give to different methods. One large donor center told us that its first step is to try to contact the donor by phone; if that approach fails, the center sends a letter to the last address, followed by a followup letter if no response is received. Finally, they turn to Trans Union. Another large donor center we met with told us that it first turns to Trans Union for each DR request that comes in.

- ***The donor retention rate at DR testing improved to 73 percent for the year ending September 1995, up from 66 percent for the year ending September 1993.***

The NMDP processed 36,012 patient-directed requests for DR testing in the year ending in September 1995, down from 38,891 in the period two years earlier. (Appendix A provides detailed data on requests made during these time periods.)

Donor centers' greatest improvement was in the *unable to contact* category. This category accounts for almost half of donors who are lost. Donor centers categorized 12 percent of DR requests as *unable to contact* during the period ending in September 1995, down from 17 percent in the period 2 years earlier.

The other three categories remained about the same over this period. *Temporarily unavailable* improved slightly, from 9 percent to 7 percent of DR requests. Those in the *medically deferred* category increased from 2 percent to 3 percent, and those who were *not interested* continued at about 6 percent.

We analyzed data for 93 donor centers that operated during this entire period. As Table 1 shows, 62 centers retained a higher percentage of donors at DR request in the year ending September 30, 1995 over the period two years earlier. In 31 centers the retention rate was lower.

Table 1 Change in Donor Retention Rate at DR Testing Year Ending September 30, 1995 vs. Year Ending September 30, 1993	
1995 Rate as a Percent of 1993 Rate	Number of Centers
120% - 140%	5
110% - 120%	16
100% - 110%	41
90 % - 100%	28
80 % - 90%	3
Source: NMDP, "Registry Statistics, October 1993" and "Registry Statistics, October 1995" Analysis by OIG/OEI	

- ▶ *For the 6 months ending September 30, 1995 donor centers' success in finding donors for DR testing ranged from 48 percent to 100 percent, with a median of 82 percent.*
- ▶ *For that 6-month period, 18 of 97 centers retained at least 90 percent of those sought for testing; 8 centers retained less than 60 percent.*

We examined in detail NMDP's data on retention at DR for requests resolved in the six month period between April 1 and September 30, 1995. During that period, donor centers received 17,781 requests for DR typing and filled 12,951 of them (73 percent). It is important to recognize that requests for DR testing are highly skewed among a few centers. Thirteen of the 97 centers received more than 50 percent of the total requests for DR typing and accounted for 48 percent of all donors that were retained during this 6-month period.

Percentage of Donors Retained at DR	Number of Donor Centers by Number of DR Requests Received			
	< 100	101-300	301-600	601-1,803
90 % - 100 %	15	2	1	--
80 % - 90 %	20	14	--	--
70 % - 80 %	7	8	6	1
60 % - 70 %	6	5	1	3
< 60 %	1	5	1	1
TOTAL	49	34	9	5

Source: NMDP, "Registry Statistics, October 1995" Analysis by OIG/OEI

As table 2 shows, the percentage of donors retained at DR is inversely correlated with the size of the donor center, as measured in the number of DR requests received. The smaller donor centers tend to retain a higher proportion of their donors than do the large centers. However, there is substantial variation within each size group, and we were unable to find a definitive explanation for these differences. One possible explanation is that some large centers operate in large geographic areas, where distance may exacerbate problems of actually getting donors to come in for testing.

Other large centers operate in urban areas, where a relatively mobile population may make it difficult to keep in contact with donors. Yet a third explanation may simply be that the differences relate to the scale of operations. For example, a donor center with 75 DR requests in a six-month period receives about 3 requests per week; on the other hand, a center with 450 requests in that period gets 2 to 3 requests per day.

- **The donor retention rate at CT testing declined to 75 percent for the year ending September 1995, down from 81 percent for the year ending September 1993, in contrast to improvements in retention at DR.**

The NMDP processed 9,454 CT requests for the year ending September 1995, a 37 percent increase over the 6,901 requests in the year ending September 1993. (Appendix A provides detailed data on requests made during these time periods.)

Donor centers' greatest difficulty in retaining donors was in the *unable to contact* category, which accounts for about one-third of the donors lost at CT. Donor centers categorized 7 percent of CT requests as *unable to contact* during the period ending in September 1995, up from 4 percent in the earlier period. The other 3 categories increased slightly over this period: *Temporarily unavailable* grew from 8 percent to 9 percent, *medically deferred* from 3 percent to 4 percent, and those who were *not interested* from 4 percent to 5 percent.

We analyzed data for 92 donor centers that were in operation during this entire period to identify how many had improved their performance (Table 3). In contrast to retention at DR, only 29 centers (32 percent) retained a higher percentage of donors at CT request in the year ending September 30, 1995 over the period two years earlier; in 63 centers the retention rate decreased.

Table 3 Change in Donor Retention Rate at CT Testing Year Ending September 30, 1995 vs. Year Ending September 30, 1993	
1995 Rate as a Percent of 1993 Rate	Number of Centers
120% - 130%	4
110% - 120%	6
100% - 110%	19
90 % - 100%	29
80 % - 90%	24
less than 80 %	10
Source: NMDP, "Registry Statistics, October 1993" and "Registry Statistics, October 1995" Analysis by OIG/OEI	

- ▶ *For the 6 months ending September 30, 1995 donor centers' success in retaining donors for CT testing ranged from 43 percent to 100 percent, with a median of 80 percent.*
- ▶ *Of 5,155 CT requests in that 6-month period, 1,279 (25 percent) donors did not come forward for testing.*

- ▶ *Twenty of 97 centers retained more than 90 percent of donors; 7 centers retained less than 60 percent.*

Table 4 presents data on retention at CT for requests resolved for the 6-month period between April 1 and September 30, 1995. As with DR retention, the smaller donor centers tended to have higher retention rates. Eleven of the 97 centers received more than 50 percent of the requests for CT tests and provided 50 percent of the donors that were retained during this period.

Table 4 Donors Retained at CT April 1995 through September 1995				
Percentage of Donors Retained at CT	Number of Donor Centers by Number of CT Requests Received			
	< 25	26-100	101-200	201-640
90 % - 100 %	17	3	--	--
80 % - 90 %	17	9	2	1
70 % - 80 %	3	14	5	2
60 % - 70 %	7	9	--	1
< 60 %	3	3	--	1
TOTAL	47	38	7	5

Source: NMDP, "Registry Statistics, October 1995" Analysis by OIG/OEI

RETENTION RATES AMONG DONORS FROM RACIAL AND ETHNIC MINORITY GROUPS LAG BEHIND THOSE FOR WHITES.

Although recruitment of minority donors has increased more rapidly than among white donors in recent years, a lower proportion of donors from minority groups are coming forward for followup testing than are whites.

- ▶ *At first level followup testing (DR testing) retention rate for minority donors improved to 66 percent for the year ending September 1995, up from 55 percent for the year ending September 1993. In comparison the retention rate among white donors grew from 71 percent to 76 percent.*
- ▶ *However, retention of minority donors at second level followup testing (CT testing) declined to 60 percent for the year ending September 1995, down from 67 percent for the year ending September 1993, while it fell from 83 to 81 percent among white donors.*

Table 5 presents data on retention rates specifically for minority donors at first level followup (DR testing) and second level followup (CT testing).

Table 5 RETENTION RATE AT DR TESTING AND AT CT TESTING FOR RACIAL AND ETHNIC GROUPS 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
White	71 %	76 %	83 %	81 %
Hispanic	56 %	63 %	70 %	62 %
Black	55 %	68 %	70 %	59 %
Asian/Pacific Islander	47 %	62 %	59 %	51 %
American Indian/Alaska Native	71 %	74 %	69 %	76 %
Totals:	66 %	72 %	81 %	76 %
Source: NMDP Registry Statistics			Analysis by OIG/OEI	

EVEN THOUGH THE DECREASE IN DONOR RETENTION RATES AT CONFIRMATORY TESTING IS SMALL, IT STILL RAISES SOME CONCERNS.

The NMDP and donor centers have gained substantial experience over the past several years. They have improved registration practices, increased donor education, adopted new technologies for locating donors, and developed continuous process improvement indicators. Consequently, we expected ongoing improvement in retention at all stages of the process, but we found that this was not the case at the CT stage. Our review identified three factors that may explain this trend:

- *Lack of direct donor involvement and commitment at the earlier DR stage.*

Donors may be less likely to feel a direct commitment at DR testing for two reasons. First, increasing numbers of donors already have been DR-typed. Some donors have been typed through an earlier patient-directed request. Other donors were DR-typed when they first joined the registry. Special funding has been earmarked to DR-type all new minority donors, and some white donors, at registration. This "front end" typing may provide one important explanation for the greater decrease in retention at CT testing for minority donors.

Second, the NMDP has recently established two central repositories. At initial registration, the donor center draws an extra sample of each donor's blood, which the NMDP stores in a repository. The donor's blood is not DR-typed at registration, but when one of these

donors is identified as a potential match, the sample is withdrawn from the repository and DR-tested.

Either situation obviates the need for the donor to physically go to the donor center at this stage. Instead, the center contacts the individual by phone to gain formal permission and to prepare the donor for the possibility that additional testing and donation are possible. These donors give their verbal permission at that time.⁸ However, they do not need to make a direct commitment in time, inconvenience, or additional blood donation until the CT stage. The director of one donor center we spoke with characterized this difference as "active" versus "passive" commitment.

- ***Potential conflict between a rapidly growing registry and donor education.***

The NMDP has experienced great success in increasing the size of the registry list. In an effort to expand their lists, some centers may not be doing an effective job of fully educating donors at initial recruitment about what will be required of them in the event of a match. The director of one donor center summarized this concern when she told us that, "If people are to come for later testing and donation, it depends on how well we do our job selling at the front end. We need to emphasize timing and commitment at every step."

Organizing registration drives is a major component of donor center work. These drives frequently focus on an individual patient in need of a transplant. On our site visits we asked donor centers "What makes a 'good' donor?" Donor centers told us that signs of a good donor include someone who reads all available material, asks serious questions, and takes time to reach a decision to join the registry. To help donors reach a decision, staff at donor centers cited extensive patient education at initial registration as critical. Donor centers told us that an important part of this educational process is ensuring that those who join the registry understand that they are not joining just for a patient who is the focus of a particular drive, but for *anyone* who may eventually need a transplant.

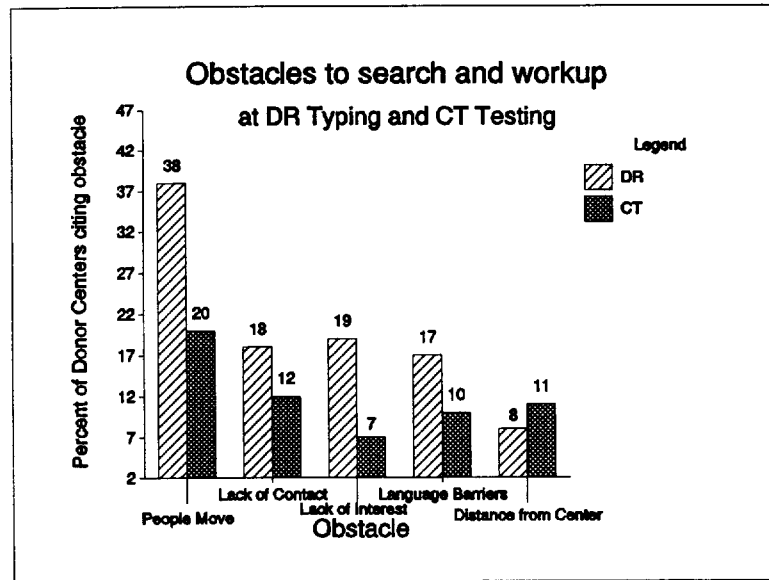
We also heard from some centers that college students are difficult to find at later stages, because they move often in their early years out of school. Several centers, however, also told us that college students were a primary target of their recruitment efforts.

- ***No awareness of problems in CT retention rate.***

Some donor centers may fail to recognize the problems we identified in retaining donors at CT. Even though donor retention is declining at this stage, donor centers responding to our survey cited obstacles to retention less frequently at CT than they did at DR.

Our survey asked donor centers about obstacles to DR and CT testing. As Figure 2 shows, with one exception (donor distance from center, where 11 percent cited it as a problem at CT versus 8 percent at DR), obstacles at DR typing were cited by about twice as many donor centers as they were at CT testing.

FIGURE 2



Source: OIG/OEI survey of domestic donor centers, August, 1995

n = 88

We raise concerns about the consequences of the declining CT retention rate for two important reasons:

- *Patient expectations are high at CT.*

When a request for CT testing occurs, a patient awaiting a transplant knows that a potential donor match has been identified. This preliminary match no doubt raises the hopes of the patient; failing to retain donors at this stage means that the patient's hopes for a transplant may have been raised unrealistically, only to be dashed because the potential donor fails to come forward.

- *Losing donors at CT is costly to patients awaiting a transplant.*

The 55 NMDP-accredited transplant hospitals bill patients a mean charge of \$264 (range = \$200-\$600) for each patient-directed DR test that is performed on potential donors. If those donors fail to come forward at CT, the patient still must pay for the DR testing that was done.

RECOMMENDATIONS

The National Marrow Donor Program (NMDP) has come a long way since its inception with a registry of 8,000 volunteer marrow donors in 1987. Today, almost 2 million donors have joined the registry, and NMDP has facilitated over 4,000 bone marrow transplants between unrelated individuals. In this report we raise concerns about the level of retention of volunteer donors on the registry list: Despite experience in recruitment and education, improvements in technology, and the implementation of continuous process improvement measures, the overall rate of donor retention has not improved.

We developed our recommendations to encourage improvement in donor retention. We believe that improving this aspect of the program will require a partnership approach between HRSA and NMDP, and between NMDP and its donor centers. Consequently, we direct our recommendations to both HRSA, as contractor for the registry, and to NMDP, as the holder of that contract.

THE HEALTH RESOURCES AND SERVICES ADMINISTRATION SHOULD SPECIFY, EITHER UPON ISSUING THE FORTHCOMING CONTRACT OR THROUGH A FUTURE MODIFICATION OF THAT CONTRACT, THE OVERALL RETENTION RATE TO BE ACHIEVED BY THE REGISTRY. To develop the appropriate retention rate, HRSA should work with NMDP and the donor centers to develop methods for improving overall retention and a plan to implement these methods. The implementation plan should include a description of actions to be taken should the registry or the donor centers fail to meet the target rates. We urge HRSA to specify target retention rates within the first year of the new contract. We also encourage HRSA to assure that these methods encourage retention of donors from racial and ethnic minority groups.

The current HRSA contract with NMDP specifies goals for overall recruitment of donors and minority donors, and for the number of transplants to be performed in each contract year. However, the contract does not contain goals for donor retention, the key middle step in that process. We urge that future contracts specify retention rates for both first attempts and subsequent attempts to contact donors. We believe that HRSA can draw on NMDP's expertise to develop minimum retention levels that can be realistically achieved.

TO THE EXTENT THAT RESOURCES ARE AVAILABLE, THE HEALTH RESOURCES AND SERVICES ADMINISTRATION, WORKING WITH THE NATIONAL MARROW DONOR PROGRAM, SHOULD SUPPORT DEMONSTRATION PROJECTS THAT TEST ALTERNATIVE STRATEGIES FOR RETAINING DONORS. We urge that particular attention be paid to demonstrations that seek to increase the retention rate among donors from racial and ethnic minority groups, including efforts to overcome language barriers that may suppress retention. We believe that any such demonstration projects should contain an evaluation component to assess the feasibility of these strategies for broader use.

The NMDP has increased substantially the number and proportion of minority donors on the registry. Donors from these groups, however, show lower retention rates than do

white donors. In addition, because an increased number of HLA combinations occur among minority groups, many minority patients face serious problems in finding a matching donor. These difficulties make strategies for improving retention rates among minority donors a priority.

NMDP SHOULD WORK WITH DONOR CENTERS TO DEVELOP AND IMPLEMENT METHODS FOR IMPROVING DONOR RETENTION AT BOTH THE FIRST ATTEMPT AND SUBSEQUENT ATTEMPTS TO CONTACT DONORS. We hope that improving retention among donors from racial and ethnic minority groups will be a focus of these efforts. We encourage NMDP also to put in place plans for evaluating the success of these methods and a strategy for disseminating successful methods to donor centers. We offer a number of options that the NMDP might use, but we also welcome additional ideas from that organization on how to achieve this goal. Possible options might include:

- *Specifying a retention rate in its operating agreement with each donor center.* The NMDP operating agreement with each donor center does not specify levels of achievement for retention at either DR typing or CT testing. Just as we urge HRSA to establish an overall goal for retention, we believe that defining minimum expectations would provide an incentive to the donor centers.
- *Augmenting performance indicators to emphasize continuous improvement over time.* The NMDP has in place performance indicators for each donor center that address retention at DR and CT. Each center receives a monthly report on its own performance on these indicators and a summary of the network's overall performance. Including monthly trend information might better inform donor centers about their progress over time and encourage ongoing improvement.
- *Enhancing donor education at initial recruitment.* Educating donors at recruitment is the first step in the marrow donation process. This education should stress the importance of timing and commitment if the donor is called for further testing.
- *Emphasizing to donor centers the need to fully educate donors when contacting them for DR testing.* In the future, an increasing proportion of donors on the registry will have their blood stored in the repository, or will have been DR typed already. This trend will exacerbate the problem of passive commitment identified in this report. Rather than merely obtaining a donor's permission through a phone call, more complete education about commitment and expectations might alleviate this problem. The NMDP could develop a script or checklist of points that donor centers should cover when contacting donors at request for DR typing.
- *Working with HRSA to devise a strategy for improving publicity around the need for retention and donor maintenance, as well as continuing current efforts on the need for recruiting donors.* Much publicity, both local and national, has been given to encouraging people to join the NMDP. Joining the registry, however, is only one step in the process. Publicity that also emphasizes the importance of commitment for those who are actually called as potential donors could help improve retention.

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 and received comments on the report from the National Marrow Donor Program (NMDP).

Use of CT and DR vs. Overall Retention

The HRSA and NMDP question why we compared changes at first level followup (DR typing) and second level confirmatory (CT) testing, rather than at first attempt and subsequent attempts to contact donors. Our analysis used DR typing and CT testing because the NMDP and donor centers use these terms. We continue to use that framework in this final report. We agree with HRSA and NMDP that it makes conceptual sense for the program to move toward reporting data in terms of first attempt at donor contact and subsequent attempts. Given developments in practice--*e.g.*, most donors now are typed initially at registration, blood samples are maintained in the NMDP repository, and DNA testing is becoming more common--this approach appears to be more appropriate.

One step that could further this reconceptualization about retention rates is for NMDP and donor centers to use that terminology. For example, the NMDP's CPI indicators continue to describe events at DR and CT testing, and data are reported using that framework. Nevertheless, we have changed our recommendations to encourage overall retention, at both first and subsequent contact attempts. We are concerned, however, that merely reclassifying how retention is described begs the larger and more critical issue that we raised in our draft report and continue to raise in this version: Despite substantial experience, which includes improved registration practices, increased donor education, use of new technologies, and the development of continuous process improvement indicators, the overall retention rate simply is not improving.

We are pleased to learn that NMDP has begun to support research to understand why donors elect not to participate when called for further testing. We hope that this research will lead to better retention rates and improve the odds of finding a donor for transplantation when needed.

Specification of retention rate

HRSA agrees with the substance of our recommendation that the contract should specify the retention rate to be achieved, but the agency raises concerns that implementing these recommendations will take longer than we recommended in our draft report. (In that draft report, we had proposed implementation prior to awarding a future contract for the registry, which HRSA notes should take place in the Spring of 1997.) We recognize that these are complicated subject areas; however, we do not believe that a complicated issue should give HRSA or NMDP latitude to take any longer than necessary to achieve them. Accordingly, we have changed our recommendation to specify the appropriate retention

rate through a contract modification, rather than prior to issuing the new contract. We urge that these changes be implemented within the first year of the new contract. We believe that such a time frame is adequate to achieve these changes.

We are concerned that an open-ended time frame could result in unnecessary delays. We wish to state clearly that developing, implementing, and enforcing performance standards and efficiency measures are important, and need to be accomplished as quickly as possible.

Developing methods for improved retention

HRSA supports this recommendation, but urges us to stress overall retention more than the DR and CT rates. We have modified the recommendation to reflect this change. We also urge the NMDP to pay attention to donors from racial and ethnic minority groups. We encourage NMDP also to put in place plans for evaluating the success of these methods, as was suggested by HRSA.

Demonstration projects

HRSA supports this recommendation. We added language to our recommendation about financing demonstration projects to encourage demonstrations that pay attention to overcoming language barriers, as recommended by the Assistant Secretary for Health. We also urge the demonstrations to contain an evaluative component to assess the broader feasibility of these demonstrations tested.

Other Comments

We have changed language in several places in the report as recommended by the Office of the Assistant Secretary for Health. ASPE had no comments on the report.

APPENDIX A

CHANGES IN DONOR RETENTION RATES

Changes in DR Retention Rates Years ending Sept 1995 vs. Sept 1993					
	DR Requests	Unable to Contact	Not Interested	Medically Deferred	Temporarily Unavailable
October, 1994-September, 1995	36,012	4,251 (11.8%)	2,186 (6.1%)	940 (2.6%)	2,550 (7.1%)
October, 1992-September, 1993	38,891	6,519 (16.8%)	2,321 (6.0%)	834 (2.1%)	3,436 (8.8%)

Changes in CT Retention Rates Years ending Sept 1995 vs. Sept 1993					
	CT Requests	Unable to Contact	Not Interested	Medically Deferred	Temporarily Unavailable
October, 1994-September, 1995	9,454	661 (7.0%)	434 (4.6%)	357 (3.8%)	835 (8.8%)
October, 1992-September, 1993	6,901	278 (4.0%)	248 (3.6%)	227 (3.3%)	578 (8.4%)

APPENDIX B

TEXT OF COMMENTS ON THE DRAFT REPORT

Health Resources and Services Administration	B-2
Assistant Secretary for Health	B-6
National Marrow Donor Program	B-8

Note: The Health Resources and Services Administration, the Assistant Secretary for Health, 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: Effectiveness in Retaining Donors."



OCT 23 1996

Health Resources and
Services Administration
Rockville MD 20857

TO: Inspector General, DHHS

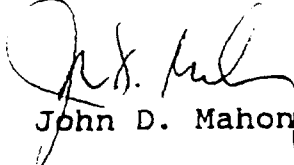
FROM: Deputy Administrator

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: Effectiveness in Retaining Donors OEI-01-95-00121

GENERAL COMMENTS

NMDP commented that the number of donors who are DR typed at enrollment has increased. The first attempt to contact donors is more often at the confirmatory testing stage rather than at the DR stage. NMDP, therefore, recommends that retention needs to be evaluated based on the "first attempt" and "subsequent attempts" to contact donors, rather than separating DR and CT retention.

OIG RECOMMENDATION:

HRSA should specify, in any future contract for operating the registry, the retention rate to be achieved. We urge that future contracts specify retention levels at both the DR and CT stages. NMDP should work with donor centers to develop methods for improving retention at CT testing.

HRSA RESPONSE

HRSA concurs with the recommendation that HRSA specify the retention rate to be achieved, but does not concur that HRSA should specify the retention rate in its next contract for operating the registry. There is insufficient time, prior to the next contract award, to develop a retention rate that is realistic and operational.

A first step is for the contractor, in consultation with HRSA, to develop target retention rates and methods for implementing them. Establishing Continuous Process Improvement (CPI) indicators for donor retention should include an adequate understanding of why volunteers are not retained and effective methods for improving retention. NMDP recommends that retention needs to be evaluated based on the "first attempt" and "subsequent attempts" to contact donors, rather than separating DR and CT retention, particularly because donors are increasingly DR typed at recruitment and contact for CT may be the first attempt to contact donors for follow-up testing. Previously, donors were contacted first for DR typing and subsequently for CT.

HRSA expects that the next contract will require a report on effective methods of improving retention and a plan for implementing continuous process improvement measures for donor retention. The implementation plan will include disciplinary actions for donor centers and recruitment groups that do not meet the CPI goals.

HRSA agrees that there is an urgent need for a thorough analysis of donor retention. As more donors are DR typed at recruitment, retention at CT reflects overall retention (DR and CT). HRSA suggests the following modification:

HRSA should work with the contractor and the donor centers to develop methods for improving overall retention, an implementation plan, and disciplinary actions. Methods for improving retention should take into account retention of minority donors as well as cost issues associated with donation.

This recommendation should precede the recommendation about demonstration projects to emphasize the importance of overall retention of donors at both the DR and CT stages.

OIG RECOMMENDATION

To the extent that resources are available, HRSA, working with the NMDP, should support demonstration projects that test alternative strategies for retaining donors. We urge that particular attention be paid to demonstrations that seek to increase the retention rate among donors from racial and ethnic minority groups.

HRSA RESPONSE

HRSA agrees with this recommendation and specifically with the recommendation that the approach to contacting donors for follow-up testing be more standardized. Evaluating alternative strategies for retaining donors and facilitating transplants should be a first step. Identifying centers that do a particularly good job at retaining donors, particularly minority donors, and noting the strategies used by them would provide valuable insights. HRSA supports the idea that HRSA work with the NMDP to identify alternative strategies and evaluate their feasibility for broader use.

OIG RECOMMENDATION:

The National Marrow Donor Program should work with donor centers to develop methods for improving retention at confirmatory testing.

HRSA RESPONSE

HRSA concurs with the recommendation, but agrees with NMDP that the overall retention rate is more important than the DR and CT rates given that more donors are being A, B, and DR typed at enrollment. Therefore, tracking retention at the first attempt

and subsequent attempts to contact donors may be more meaningful than retention at DR and CT.

The OIG Report suggested possible options for improving retention at confirmatory testing. Some of these options, such as specifying a retention rate in the operating agreement with each center, require consideration and development. In addition, development of strategies to improve retention, including donor education and publicity, is important but may not need to be specified.

Additional strategies, directed at facilitating the transplant process by improving retention, may be even more important but more difficult to develop. Therefore, some mention of evaluating as well as implementing strategies for maintaining contact with donors might be useful.



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Office of the Secretary

AUG 28 1996

Assistant Secretary for Health
Office of Public Health and Science
Washington D.C. 2020

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.



September 4, 1996

National Marrow
Donor Program

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Claude Lenfant, M.D.

A collaborative effort of the

American Association
of Blood Banks

American Red Cross

Council of Community
Blood Centers

With funding from:

Health Resources and Services
Administration and
Naval Medical Research and
Development Command

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.

Effectiveness in Retaining Donors

A recurring theme throughout the comments on this section was how retention should be defined and quantified. The conclusion of the draft report was that the situation was improving for "DR retention," but deteriorating for "CT retention." In fact, most donors contacted at CT are being contacted for the first time. Very few DR typings lead to subsequent CT typing since DR typing only rarely produces a match. Thus it is not surprising to see that the DR and CT retention rates are converging at 75% in light of the fact that both represent the first attempt to contact a donor. An alternative would be to evaluate retention on the basis of "first attempt" versus "subsequent attempts."

There were reservations expressed about the establishment of continuous process improvement indicators for donor retention. These reservations centered on two premises: 1) An inadequate understanding of why volunteers are not retained; 2) An imprecision and overlap in the categories (NI, TU, etc.) used to describe donor status and a resultant concern that factors over which donor centers have no control would be used to rate (reimburse) them. To obtain better information about the first premise, Galen Switzer, Ph.D. of the University of Pittsburgh is about to embark upon a study of the reasons NMDP donors elect not to participate when called for further testing.

The report recommendation for a more standardized approach ("script or checklist of points") to contacting donors for follow-up testing was thought to be beneficial.

An appropriate caveat in comparing the ability of donor centers to retain donors was that of donor center age. Comparison of retention rates for "old" centers (many volunteers having been recruited five or more years ago) versus "young" centers are inherently inequitable.

It was well recognized that many of the ideas for improving donor retention were likely to come with a significant cost. It was agreed unanimously that an increased sensitivity to donors and their concerns on the part of donor center personnel was both desirable and cost effective.

Recommended Modifications to the Draft Report:

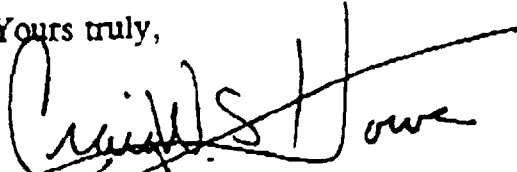
- The improving DR retention and deteriorating CT retention is an artifact caused by the fact that increasing proportions of requested donors have already been DR typed. We need to compare effectiveness at first donor contact, whether for DR or CT.
- Factors involved in donor retention are too complex for a simplistic comparison of retention rates. We agree that there is an urgent need for a thorough analysis of this problem, which we have already begun.


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 C

ENDNOTES

1. National Marrow Donor Program, *The Living Gift of Life*.
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. §274k(b)(1)-(7)
4. Grant money from the Office of Naval Research pays for minority donors to undergo initial HLA-DR typing, which is a higher level of testing than most Caucasian donors would initially undergo.
5. Ninety-five percent of new donor centers have blood samples sent to one of two NMDP repositories. When a potential donor is contacted for DR typing, the donor's blood can be directly sent from the repository to a lab for testing. However, the donor must still be contacted for consent.
6. In addition to the DR typing and additional confirmatory testing, the donor center is responsible for ongoing donor management. This can be a lengthy process, involving counseling, advocacy and other aspects of donor education.
7. The accuracy of this system is unclear. During our research, a donor center performed a search using Trans Union for the two OEI interviewers. One OEI staff member, in his mid-40s and residing in the same home for 8 years, appeared accurately in the system.

The second OEI staff member, in her mid-20s, yielded much less reliable data. Using her social security number, Trans Union listed the university from which she graduated 5 years earlier as her most current address, even though she had moved half a dozen times since then. A second search using her last known address posted the true second-to-last address but listed her as having an old telephone number and incorrect social security number.

While we do not generalize from this sample of two cases, our experience raises an important concern that NMDP and donor centers need to be aware of: College students are a prime recruiting target for NMDP donor centers. Such people move frequently in their years immediately following graduation, making them difficult to track down in response to DR and CT requests. But our experience makes it questionable if the software is up to the task required.

8. Most donor center staff with whom we met informed us that they phoned donors whose blood was in the repository. They try to contact them just as they would donors who have to go a blood center to have blood drawn for further testing. During our site visits, however, we met with staff from one donor center that simply forwarded the request to the repository, and tried to make contact with the donor only at the CT stage.