

Section 2: Contract Components

2.0 C.W. Bill Young Cell Transplantation Program

The four components of the C.W. Bill Young Cell Transplantation Program are:

- Office of Patient Advocacy and Single Point of Access (OPA/SPA)
- Bone Marrow Coordinating Center (BMCC)
- Cord Blood Coordinating Center (CBCC)
- Stem Cell Therapeutic Outcomes Database (SCTOD)

2.1 Office of Patient Advocacy and Single Point of Access (OPA/SPA)

Patients who are facing a life-threatening illness may need help in understanding their disease and their treatment options. When a patient needs a bone marrow, peripheral blood stem cell or cord blood transplant, the OPA can help the patients, their families and health care providers make sense of the options that are available. The C.W. Bill Young Cell Transplantation Program was created to help more patients have a successful HCT. As one of the four components of the C.W. Bill Young Cell Transplantation Program, the OPA/SPA provides help and support to patients and families.

The OPA helps by providing case management services and information directly to the patient and their physician from the time of diagnosis through survivorship. OPA also increases access to transplants by reducing barriers and providing services that are linguistically and culturally sensitive. Having a Single Point of Access means that doctors, transplant center coordinators, patients and patient families can use one electronic system to search the Registry for unrelated marrow and peripheral blood stem cell donors as well as for CBUs.

2.1.1 New Mission/Contract Requirements

Since it was started in 1991, the NMDP's OPA has supported patients, families and caregivers throughout the transplant journey. The field of transplantation continues to evolve as the number and diversity of patients who receive a transplant from an unrelated donor or CBU grows, the average age of patients continues to increase, and the number of transplant survivors in the United States grows. However, disparities exist for patients and families from some groups. Barriers and burdens prevent access to transplant and prevent some patients from receiving the best medical care, information and advocacy after their transplant.

The services that are available for patients, families and health care professionals through the OPA/SPA include:

- Culturally and linguistically sensitive information about diseases, treatment options and transplant centers. This information takes the form of:
 - Programs and tools such as Webcasts, teleconferences and online tools that reach a wider national audience
 - Educational resources in a variety of formats (e.g. patient teleconferences, audio and video, print, Web)
- Individualized case management services to help patients deal with a variety of issues, locate resources and access educational information
- Services to identify and resolve barriers for patients needing a transplant, including barriers associated with the financial coverage of costs to perform a donor search and to receive a transplant
- Partnerships with other professional and patient advocacy organizations to expand public awareness

- Preliminary search access for transplant centers, patients and physicians to look for unrelated bone marrow, peripheral blood or cord blood matches
- Collaboration with the bone marrow and cord blood coordinating centers to provide a single point of access to transplant-related services:
 - Compiling search results received from the coordinating centers
 - Providing customized search assistance
 - Providing consultation about tissue type matching (HLA) as needed

The OPA/SPA patient advocacy goals are to:

- Provide a system to support individual patients and their efforts to identify and work with a transplant center
- Provide technical assistance to help patients at transplant centers and to supplement patient advocacy services at transplant centers that have limited resources
- Identify barriers to patients receiving a transplant, especially transplants from unrelated donors, and to provide assistance for overcoming them
- Assist individuals in obtaining insurance support and other sources of financial aid
- Assess the post-transplant needs of patients (as a group) and provide educational materials to help them understand and meet those needs
- Provide support and information to caregivers of patients, and
- Increase awareness of the services offered through the OPA

Details about how the OPA and SPA are working toward meeting these goals follow.

2.1.2 Patient advocacy services and case management

2.1.2.1 Contacts with the Office of Patient Advocacy (Statistics)

Information is tracked about how patients, families, health care professionals and other patient advocacy organizations are connected to the OPA, whether that is through patient services coordinators, search advocacy and patient assistance program contacts, customer satisfaction survey responses or requests for materials. Patient demographics, insurance denials, requests for financial assistance and changes in transplant volume for various age groups and diseases are also studied. The OPA uses this information to develop, evaluate and improve patient programs and services. Table 1 illustrates these OPA contacts throughout the transplant process for 2008-09.

- *Direct* patient contacts are made in person, by phone, mail or e-mail.
- *Indirect* patient contacts are through health care professionals or patient organizations and via visits (hits) to the MatchView® Web site page.

Table 1 describes the Office of Patient Advocacy contacts.

NMDP Office of Patient Advocacy Contact	2008 Amount	2009 Amount
Physician preliminary search: Helping referring physicians not associated with an NMDP transplant center run a preliminary search for their patient	856	555
Performance of a non-network search (formerly called compassionate)	386	285
MatchView® Web hits (unique visitors to this page)	9,262	9,787
MatchView application button pressed	(1,152 ²)	(5,098)
Preliminary search packets: A packet sent to all patients in the U.S. who have had a preliminary search for an unrelated donor performed on their behalf. It contains the following information: <i>Step One</i> booklet, <i>Mapping the Maze</i> (financial guide), letter from the OPA director, patient satisfaction survey and materials order form.	7,829	8,417
Attendance at case manager telephone education workshop entitled <i>An Introduction to Marrow & Cord Blood Transplant</i> held quarterly, survivorship workshops held annually, and fundraising workshop (2009)	199	502
Requests for case management: Contacts with patients, family members, and others acting on behalf of patients (phone calls and emails) ³	17,588	18,870
Educational material requests filled and sent to patients (and others)	1,690	1,406
Formal search packets: OPA sends a packet of information to patients involved in a formal search	5,517	5,899
Office of Patient Advocacy Survey: mail surveys returned. These surveys are sent to those who contact OPA or sent to those who were contacted as part of the Outreach Program	238	216
Patient Assistance Program (Search Assistance Funds): contact is through the transplant center coordinator or social worker who works directly with the patient/family to apply for financial assistance for search-related costs	720 grants	863 grants
Patient Assistance Program (Transplant Support Assistance): contact is through the transplant center coordinator or social worker who works directly with the patient/family to apply for modest financial assistance for post-transplant needs	3,124 grants	4,381 grants
<i>Living Now</i> Newsletter—Post-transplant educational newsletter sent to NMDP patients at 6 intervals after the transplant (3 months, 6 months, 9 months, 12 months, 18 months and 2 years)	10,705	12,033
TOTALS	58,114	63,214

Table 1. Office of Patient Advocacy contacts

2 A report to track online submission of the MatchView application was begun in October 2008.

3 These numbers reflect contacts made as part of the Patient Services outreach program.

2.1.2.2 Using MatchView®

In May 2007, the NMDP launched a new Web-based resource for patients called MatchView, available at the NMDP website (<http://www.marlow.org/>). This allows patients to enter their HLA typing and view the number of potential matches (donors and CBUs) on the NMDP Registry. Patients can print a summary to use in discussions with their physician. The purpose of MatchView is to help patients and their oncologists or primary care physicians discuss unrelated donor transplantation and the appropriate next steps if a transplant is an option. This resource helps people interpret the results of their preliminary search for a matched donor, including information about whether donors and CBUs are available, and if they need to work with a transplant center to initiate a more comprehensive unrelated donor search. NMDP patient services coordinators and search advocates also help patients access MatchView by mail or fax, and will help them interpret the search reports by phone. Interpreter services are available for those who need assistance.

Non-network searches. Some potential transplant recipients do not live close enough to an NMDP transplant center to use its services. If a patient must temporarily move to be near an NMDP transplant center, they may face financial barriers or not have a caregiver available. A patient may also live in a country that does not currently have an NMDP transplant center. The non-network search process helps non-NMDP transplant programs search the NMDP Registry and perform a transplant for their patients with an NMDP donor or CBU. Transplant programs that request non-network searches are pursuing membership with the NMDP, but have not been approved yet because the application is in process.

2.1.2.3 Providing Transplant Information for Patients

The OPA/SPA gives information and educational materials to patients and family members that are tailored to specific ages, cultures and languages. This includes information about the following topics:

- Diseases that are treatable by a transplant
- The search and transplant process
- Patient-focused donor drives
- Financial resources
- Information about specific transplant centers
- Post-transplant information and resources

Patients can find these programs and services in a variety of ways, including through one-to-one contact with an NMDP patient services coordinator, materials distributed to referring physicians and transplant centers, partnerships with other patient organizations, and through two Web sites <http://www.marlow.org> and <http://bloodcell.transplant.hrsa.gov>.

2.1.2.4 Transplant center-specific survival data

Survival data from specific transplant centers is available to patients, families and health care providers through the publication entitled *Choosing a Transplant Center: a Patient's Guide*. This guide is published each year in print and online, and lists every NMDP transplant center in the United States. Contact information, the number and type of transplants the center performs (e.g. marrow, peripheral blood stem cells, cord blood, pediatric and/or adult), match criteria, estimated costs, and financial services for each center are all included in the guide.

A description of each center looks at many factors that are known to influence transplant success, such as the age of the patient, their diagnosis, disease stage, general health, etc. The results that are shown in the Center-Specific Analysis section of the guide can be used to compare the performance of a particular center with other NMDP U.S. transplant centers. The results that are considered in each center's performance are:

- The disease conditions of patients who receive a transplant at the center
- The predicted one-year survival rate
- The actual one-year survival rate of patients who receive a transplant

The online version of the guide can be found at <http://www.marlow.org/access>. Current center-specific survival data focuses on transplants with unrelated donors at U.S. centers.

2.1.2.5 Surveys of Patient Satisfaction

The OPA/SPA administers two surveys to patients who interact with NMDP: a Patient Satisfaction Survey and an Office of Patient Advocacy Survey. The information from these surveys is used to plan and develop future programs and services. It also helps OPA/SPA determine if they are meeting patients' needs and find ways to improve their services.

- The Patient Satisfaction Survey is mailed to all U.S. patients who have participated in a preliminary or formal search of the NMDP Registry. These patients are sent OPA/SPA's education and information packets, which include the Patient Satisfaction Survey.
- The Office of Patient Advocacy Survey is sent to anyone who has direct contact with a patient services coordinator and for whom a mailing address is available.

The Patient Satisfaction Survey allows the OPA/SPA to learn whether individuals who have received a transplant information packet from NMDP are satisfied, and if the information and services the office has provided are meeting patient needs. A total of 22,896 surveys were mailed between January 2008 and December 2009. Of these, 2,464 were returned (10.8% response rate). Survey respondents are not given an incentive for returning the survey and surveys are sent only once to each individual. However, a study to examine the impact of incentive and follow-up was conducted from July 2009 to September 2009. Response rates significantly increased with both approaches. The experimental group had a 50.5% response rate compared to the control group, which had a 12.8% response rate ($p < .05$).

Responses to a few of the Patient Satisfaction Survey's most important questions are provided in the tables below.

Table 2 shows the responses to the question: How have you used the information from the NMDP's Office of Patient Advocacy?

Survey Question: How have you used the information from the NMDP's OPA?	2008 Responses	2009 Responses
It is my main source of information	216 (21%)	293 (22%)
I use this as well as other information	795 (75%)	980 (73%)
I do not use this information	43 (4%)	68 (5%)

Table 2. How have you used the information from the NMDP's Office of Patient Advocacy?

Table 3 shows the responses to the question: What will you do because of this information from the NMDP's OPA?

Survey Question: What will you do because of this information from the NMDP's OPA?	2008* Responses	2009* Responses
Use as reference	882 (83%)	1110 (82%)
Share with family	838 (78%)	1095 (81%)
Review with doctor	577 (54%)	698 (51%)
Visit http://www.marlow.org	559 (52%)	685 (50%)
Contact additional resources	331 (31%)	448 (33%)
Review with hospital staff	288 (27%)	355 (26%)
Contact OPA	256 (24%)	312 (23%)
Nothing further	16 (2%)	27 (2%)

Table 3. What will you do because of this information from the NMDP's OPA?

Figure 2 shows how patients use OPA materials.

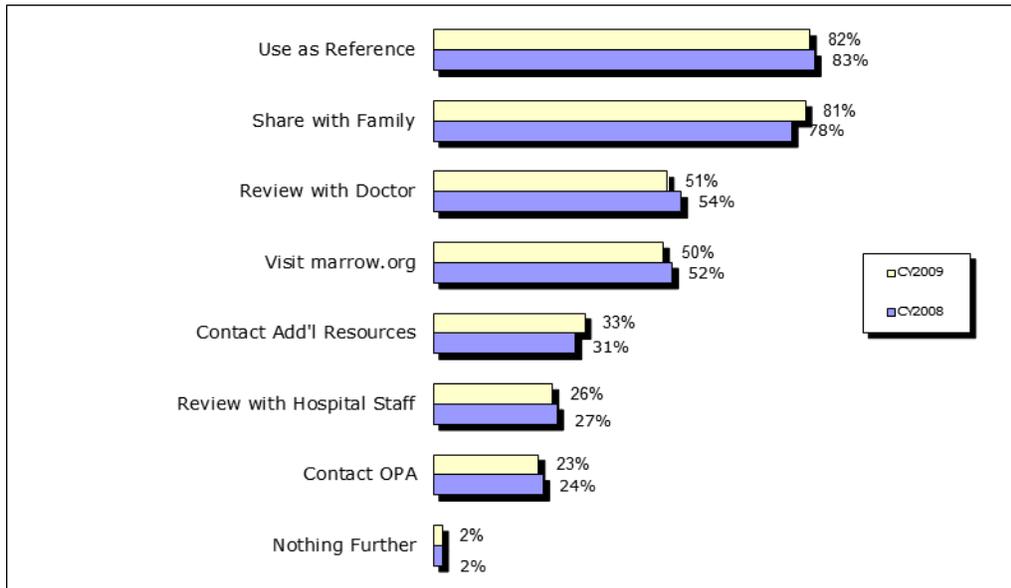


Figure 2. How patients use OPA materials.

The Office of Patient Advocacy Survey is an important tool for the OPA to elicit feedback from patients, caregivers and others who use their case management services. A total of 1,870 surveys were mailed between January 2008 and December 2009 to people who had direct contact with a patient services coordinator. Of these, 454 were returned (24% response rate), which includes 11 responses to the 77 Spanish surveys distributed (14% response rate). The tables below provide responses to selected questions taken from the survey. Table 4 gives a breakdown of whether the survey was filled out by the patient, relative/friend or other person.

* 2008 number of responses = 1082; 2009 number of responses = 1382

Question: Who completed the survey?	2008 Responses	2009 Responses
Patient	121 (54%)	128 (61%)
Relative or friend	104 (46%)	79 (38%)
Other	1 (<1%)	2 (1%)

Table 4. Person filling out the OPA survey

Table 5 shows the responses regarding what other information might be helpful. The request with the highest response was for post-transplant information. A post-transplant annual teleconference and other initiatives are also being offered to meet this need. All of the survey information is presented to the NMDP's Patient-Focused Initiatives Committee to help them plan future programs and services that OPA can offer to benefit patients.

Question: What other information or services might be helpful?	2008* Responses	2009* Responses
Post-transplant information	104 (59%)	105 (64%)
Talking to another person	93 (53%)	81 (50%)
Age or disease-specific information	77 (44%)	87 (53%)
Information for caregivers	65 (37%)	46 (28%)
Support group	58 (33%)	56 (34%)
Teleconferences	22 (12%)	26 (16%)
Other	13 (7%)	13 (8%)

Table 5. What other information/services regarding transplant would be helpful? (Respondents were asked to check all that apply and could add other recommendations.)

Table 6 shows the responses to the question: Would you recommend the OPA to someone else in your situation?

Question: Would you recommend the OPA to someone else in your situation?	2008 Responses	2009 Responses
Yes	214 (94%)	200 (94%)
Maybe	8 (4%)	8 (4%)
Don't know	4 (2%)	3 (1%)
No	2 (<1%)	1 (<1%)

Table 6. Would you recommend the Office of Patient Advocacy (OPA) to someone else in your situation?

2.1.2.6 Patient Advocacy Efforts

Following are the major undertakings of the OPA/SPA each year:

1. Provide a system to support individual patients and their efforts to identify and work with a transplant center.

The OPA/SPA provides a variety of individual advocacy services to patients, families, caregivers and health care professionals throughout the transplant process. This is a priority area, so the OPA/SPA offers the following services:

- One-to-one telephone support to patients, families and health care professionals who contact the OPA.
- Problem resolution for patients and their physicians searching for an unrelated donor or CBU.

- Guidance and modest financial assistance to patients and families in need, for donor searches and post-transplant costs.
- Advocacy and telephone outreach for transplant families, to help them find additional resources (through the Patient Outreach Program).
- Resource finding, such as locating fund-raising organizations, travel and lodging assistance, and other disease-specific organizations that can provide direct services to patients and their physicians.

The number of individual contacts made in calendar year 2008-09 through these services is highlighted in Table 1 (above).

2. Provide technical assistance to enhance patient advocacy programs at transplant centers and supplement advocacy services at transplant centers that have limited resources.

The OPA/SPA develops new programs and improves existing programs to help patients throughout the transplant process. These programs provide services that are appropriate to different patient demographics such as age, language, culture, literacy and learning preferences.

New programs and tools that have been created or are in development include:

- **Online clearinghouse.** Throughout FY 2009, the OPA and nine partner organizations worked to develop an online information clearinghouse tool for transplant patients, caregivers and family members. The envisioned online “clearinghouse” will serve as the central place to manage transplant information and make it more available. The clearinghouse is intended to better serve transplant patients and their families throughout the treatment continuum by providing them targeted, relevant information; to help them learn what “they need to know now.” The launch of the clearinghouse is planned for early summer of 2010.
 - **Words of Experience. Stories of Hope.** This DVD, intended for adult patients and caregivers, focuses on various components of the transplant process within a hospital setting. It features interviews with patients, caregivers, physicians and other transplant center staff to help viewers understand what to anticipate during orientation to their transplant center, the preparative regimen, the actual transplant procedure, engraftment, and early recovery. Special features include information on such procedures as chemotherapy and radiation. The DVD can be viewed in English and Spanish. More than 30 transplant center staff volunteered to serve as content reviewers throughout the development of this resource.
3. Identify barriers to transplant, especially non-HLA-related (tissue type) obstacles, and provide assistance for overcoming them.

The transplant process that patients and family members experience—from diagnosis through survivorship—may include barriers and burdens that limit their access to transplant services or impact its success. Each year, the OPA assesses the educational needs of the patients, families, and caregivers served by the Program.

The NMDP’s Health Services Research (HSR) program was formally established in FY 2008. HSR is the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately health and well-being (Academy Health, 2000). The HSR team engages in collaborative research with CIBMTR; consults with OPA staff concerning research designs and methodologies; evaluates OPA programs, services and materials; assesses patient satisfaction with OPA services and

materials; helps translate research into practice, seeks to optimize practice through research; and disseminates evaluation and research results.

In April 2009, a new Payor Relations Manager was hired. This person focuses on building relationships with payor stakeholders, public and private, and developing tactical strategies for identifying and removing financial barriers facing patients. During the remaining months of FY 2009, the majority of the Payor Relations Manager's time was spent discussing major coverage and reimbursement policy concerns expressed by network transplant centers and patient families.

4. Assist individuals in obtaining insurance support and other sources of financial aid.

The OPA/SPA receives numerous calls each week from patients and families about their financial or insurance concerns, including requests for financial assistance. The OPA/SPA helps patients who:

- Have no insurance and need information on insurance programs;
- Are underinsured or lack adequate insurance coverage for donor search costs;
- Have been denied coverage for a transplant by their insurer; or
- Have financial barriers after their transplant, including difficulty paying insurance premiums, paying for drugs, or other non-medical post transplant costs associated with their care.

One of the key services offered through the OPA/SPA is the Patient Assistance Program. The Patient Assistance Program provides financial grants to patients who need an unrelated marrow or cord blood transplant and are in need of assistance. This program offers a Search Assistance Fund and a Transplant Support Assistance Fund.

The goal of the Search Assistance Fund is to increase access to transplants for patients who have inadequate insurance coverage. Fifty-eight percent of patients who received Search Assistance Funds in 2009 (57 percent in 2008) went on to have an NMDP-facilitated transplant.

Patients and families often have significant increases in their expenses after a transplant, at the same time they are experiencing a reduction in income. On average, patients and families reported a 31 percent reduction in monthly household income at the time they apply for financial assistance. The Transplant Support Assistance Fund provides grants to patients or families who have expenses that are not covered by insurance during the period following their transplant. Eligible expenses include food, ground transportation, temporary lodging, prescriptions and clinic co-pays, and insurance premiums.

In addition, OPA is a member of the Cancer Financial Assistance Coalition (C-FAC), which consists of 12 national financial and/or prescription assistance programs. This coalition, facilitated by CancerCare, came together in 2007 in order to:

- Facilitate communication and collaboration among member organizations;
- Educate patients and providers about existing resources and linking to other organizations that can disseminate information about the collective resources of the member organizations; and
- Advocate on behalf of cancer patients who continue to bear financial burdens associated with the costs of cancer treatment and care.

With the realization that each organization participating in the coalition offered lists of other financial resources to approach for help, in 2009 C-FAC developed a clearinghouse to provide a single, extensive listing of local and national financial resources to help patients and their families more easily access this information. This clearinghouse is available at:

<http://www.cancerfac.org>.

5. Assess and meet the post-transplant needs of patients.

More patients live longer after a transplant than in the past, but many have ongoing health problems. After a transplant, patients and their caregivers can face many physical, financial and emotional challenges. Most transplant survivors have long-term effects or complications. These can include chronic and debilitating immune system disorders, fatigue, memory and concentration problems, infertility, and an increased risk of secondary cancers. The medical, financial and emotional costs of a transplant continue well into recovery and can burden patients and caregivers for years.

Programs and resources that have been developed in 2008 and 2009 to respond to these post-transplant needs of patients include:

- **Emotional Health after Transplant for Survivors and Caregivers brochure.** This brochure provides information for survivors on how to address emotional health issues after transplant, but its audience now includes both survivors and caregivers. It discusses the anticipated emotional responses to transplant for survivors and caregivers, methods to improve and maintain their emotional health throughout the transplant continuum, and questions to discuss with their physicians. The brochure also provides a list of national resources and support dedicated to addressing mental and emotional health needs throughout the transplant process. This brochure was developed with content support from CancerCare and The Wellness Community national offices.
- **Survivorship telephone education workshop.** Based on feedback from post-transplant patients and evaluation results from a 2008 survivorship event, another survivorship telephone education workshop was developed and offered in FY 2009. The goal of this year's program was to expand existing resources for patients who had a marrow or cord blood transplant and to provide information on a topic that survivors had indicated is of interest to them. The free telephone education workshop entitled Living Now: Your Post-Transplant Road Map was held in Sept. 2009. The primary speaker for this workshop was Willis H. Navarro, MD, Medical Director, Transplant Services, at the NMDP. Objectives included learning more about possible late effects; recommendations for prevention and monitoring for late effects of transplant; how to take an active role in post-transplant care; and survivorship resources. The majority of the 203 participants in this education program indicated they were marrow and cord blood transplant survivors.

6. Provide ongoing support and information to caregivers of patients.

Providing direct care for a recovering transplant patient is easily a full-time job, often involving a significant amount of psychological and emotional stress for the caregiver. It is not uncommon for a transplant caregiver to experience symptoms of depression and anxiety, even post-traumatic stress disorder, at numerous points throughout the transplant continuum⁴. Because there is often more focus on the patient's needs, the caregiver's needs often go unaddressed.

Several new programs and resources were developed in FY 2009 to focus on information for caregivers and health professionals who work with caregivers. They include:

- A research pilot study was conducted through the OPA in conjunction with Michelle Bishop, PhD, University of Florida Department of Medicine, for caregivers of transplant recipients. The purpose of the study was to evaluate a caregiver self-care toolkit for

4 Bishop, M., Beaumont, J.L., Hahn, E.A., Late Effects of Cancer and Hematopoietic Stem-Cell Transplantation on Spouses or Partners Compared with Survivors and Survivor-Matched Controls. *Journal of Clinical Oncology*. Vol. 15, No. 11, Apr 10, 2007.

content, feasibility, mode of administration (self-administered versus coach-facilitated) and effects of caregiver stress and coping. The University of Florida arm was self-directed while the OPA arm of the pilot study utilized a coach-assisted model.

- In order to respond to the unmet needs of the caregiver community, the OPA developed a special Living Now issue for caregivers. The primary goal of the caregiver issue is to provide transplant caregivers with an educational and directional resource to help them better care for themselves throughout the transplant continuum. Thus, this issue focused on supporting the caregiver's needs – and not on what the caregiver needs to do to support their loved one. This special issue was completed in September 2009.

7. Publicize the services offered by OPA/SPA.

OPA/SPA participates in numerous national activities to increase awareness about its resources and services to various audiences, including patients, families and caregivers, health care professionals, and other patient-focused organizations. These activities allow the OPA to reach these other groups, identify collaborative opportunities and gain knowledge to use for new projects and resources.

Some of OPA/SPA's publicity activities include:

- Conducting site visits to transplant centers.
- Participating in national and local patient-advocacy, payor and financial, and professional association conferences and events as presenters, exhibitors and attendees. The primary objectives for participating are to increase awareness of marrow and cord blood transplantation; increase the visibility of OPA programs, services and materials; network with internal and external contacts; and identify new partnership opportunities.
- Creating national teleconferences that provide greater access to transplant information for patients and families across the country.
- Providing a comprehensive catalog of OPA/SPA resources.
- Collecting stories from patients – sharing tips and advice with other patients, families and caregivers.

2.1.3 Provide a Single Point of Access (SPA)

As the point of access for physicians and patients to initiate searches of all registered adult donors and CBUs in the United States and internationally (through cooperative agreements with international registries), the NMDP provides an efficient search process through one electronic system. Doctors, transplant center coordinators as well as patients and their families can use this system to search the Registry. This process includes:

- Allowing patients and doctors to explore the possibility of finding a donor or CBU using an easily accessed electronic interface
- Worldwide searching for all sources of blood stem cells
- Allowing doctors and transplant centers to reserve a CBU or initiate further testing of a potential volunteer donor
- Providing updates of the search progress to patients, doctors and transplant centers

2.1.3.1 Compile Search Results Received from Coordinating Centers

NMDP consolidates search results from the Bone Marrow Coordinating Center (BMCC, Section 2.2) and Cord Blood Coordinating Centers (CBCC, Section 2.3). It provides electronic search reports to transplant centers for donors and CBUs listed on its Registry through an Internet search program called Traxis™. The program is used by transplant centers to manage and

track the entire search process and to access unrelated adult donors and CBUs worldwide, from initial search to transplantation.

- **HapLogicSM.** In 2006, NMDP introduced an enhanced matching program that automatically identifies the donors or CBUs on the NMDP Registry with the highest potential to match a patient. This allows transplant physicians searching the Registry to identify more quickly and efficiently the best matched donor or CBU for their patients. The matching formula, referred to as HapLogicSM, is based on analyses of the tissue types (HLA) of millions of donors on the NMDP Registry. HapLogic uses advanced computer logic to predict the likelihood of finding matching donors or CBUs. In FY09, the NMDP initiated the planning process for the next enhancement of the HapLogic algorithm. This phase will work to establish HLA matching predictions for donors and CBUs that will utilize more extensive population genetics data and improve the donor sort to meet the clinical standard practice in transplantation.
- **Search services support.** NMDP provides several services at no charge to transplant centers or patients to help them rapidly identify the best potential donor or CBU for further testing. NMDP staff with HLA matching expertise review preliminary search results and suggest search strategies for those patients with HLA types that are difficult to match. HLA consultations are available at any time in the search process. Consultants may be contacted at the request of transplant center staff or when an NMDP search coordinator identifies a problem with a search, such as too few donors or no sufficient matches among the donors already tested. NMDP also provides a centralized search management service for transplant centers that choose to request donor selection and monitoring services from NMDP. Transplant centers using this service have noted a decrease in search costs, reduction in search times, and increase in transplants.

2.1.3.2 Monitor Progress of Searches and Follow Up on Dormant Searches

The OPA, Search and Transplant Services, and Scientific Services staff members from NMDP work together to ensure that patients' searches can lead to a transplant without delay. Staff members who are involved in the search monitoring process have expertise in the biology of HCT, the unrelated donor search process and in tissue (HLA) compatibility. Staff members from the various teams coordinate their efforts to eliminate barriers throughout the search process:

- Patients with inadequate financial resources for search fees may receive patient assistance funds or help working with their insurer.
- Searches with only a few potential donors are referred for an HLA consultation to identify the best donors available. The HLA consultant can offer insights into the patient's HLA typing and the probability of finding a suitable donor or CBU for a transplant.
- Patients searching via network transplant centers usually get search status updates from their transplant center coordinator. This gives the transplant center an opportunity to work with their patients on both search and non-search related issues (e.g. patient's health status, housing for family members during the transplant, etc.). Transplant centers get instant updates on their patients' searches through the TraxisTM software application. NMDP provides search status updates to patients through its OPA/SPA case management staff.

2.1.3.3 Quality Control Plan

NMDP has quality monitoring and control processes in place for many of its activities, including HLA typing laboratories, transplant center search management proficiency, computer searching enhancements, and blood stem cell collection and shipping. NMDP's application testing process includes documentation, manual testing and automated testing.

2.1.3.4 Protecting the Confidentiality of Donors and Patients

NMDP complies with federal privacy laws to ensure that data and search reports protect the confidentiality of donors and patients. It maintains strict confidentiality policies through documented procedures, employee training, and published Donor and Patient Confidentiality Guidelines. All employees participating in human subject research studies have completed training in how to ensure patient privacy and safeguard the rights of research subjects with an online course through the Collaborative Institutional Training Initiative (CITI) program.

2.1.4 Patient Education Plan

It is a priority for the OPA/SPA to provide accurate and accessible educational resources for patients, families and health professionals on all aspects of the transplant process. This ensures that people who are considering or receiving a marrow, peripheral blood stem cell or cord blood transplant can make thoughtful, informed decisions. OPA gives special consideration to the varied learning styles and cultural needs of patients, families and care givers, especially those from medically underserved communities. Patients from special populations may experience greater challenges in accessing quality care and information about their disease. The OPA seeks to provide readily understood, medically accurate information for all individuals, in a variety of formats that respond to the broad range of learners' abilities, needs and preferences.

Each year, the OPA/SPA develops a plan that outlines the educational resources available through NMDP and OPA/SPA for patients, families and caregivers. The plan covers the four areas of the C.W. Bill Young Cell Transplantation Program: the BMCC, CBCC, SCTOD and the OPA/SPA. It also describes the OPA/SPA approach to evaluating the effectiveness of patient materials and resources.

2.1.5 Professional Education Plan

The NMDP, through the OPA/SPA, delivers significant and sustained professional medical education programs and resources to support physicians who refer patients for a transplant and who treat patients following transplantation. These educational programs focus on four key areas: refer, select, streamline and care.

2.1.5.1 Refer

Educate and enable referring physicians to refer appropriately. The referring physician plays a key role in positive outcomes for transplant patients. Data about outcomes clearly show the importance of the timing of the transplant. For most diseases, there is a survival advantage for patients transplanted earlier in their disease process. Research conducted by NMDP showed that referring physicians often do not have sufficient education about the role and timing of transplants⁵. Those physicians with greater knowledge about transplant were more likely to recommend it to their patients. Referring physicians also showed a strong allegiance to their local transplant center's expertise. In response to what was learned in this study, NMDP has developed and implemented an outreach program to educate referring physicians on three key messages: 1) transplant outcomes have improved, 2) appropriate timing of the referral improves outcomes, and 3) patient eligibility has expanded.

The OPA/SPA provides education and resources to referring physicians in two ways: directly from NMDP and by supporting network transplant centers in their local educational activities with community physicians. NMDP provides both logistical support and educational materials that have been specifically developed to overcome barriers to referral.

⁵ NMDP Market Research Findings 2006.

Educational resources that are available include the Quick Reference Guidelines tool kit. This kit includes the referral guidelines, Recommended Timing for Referral Consultation and Post-Transplant Guidelines, and a slide presentation that can be tailored to center-specific processes. National efforts in the past two years have included more promotion of the online resources, sponsoring numerous national Continuing Medical Education (CME) programs on the role and timing of transplantation. Currently seven online CME programs are available and additional programs are planned, to provide frequent updates on advances and recent outcomes data.

NMDP has also partnered with an education provider to expand viewership, resulting in a 400% increase compared with previous methods. Newsletters, mailings that promote these resources and mailings that reinforce messages from the CME programs offer guidance and support to community physicians. Recent advances in cord blood transplantation, including better outcomes and better access to transplantation, have been important elements of these communications. In addition, NMDP has led a collaboration among several other transplant societies and organizations to raise awareness of the advances in transplantation.

2.1.5.2 Select

Lead the transplant field in understanding and applying the best practices in donor and cord blood selection. The OPA/SPA educates participants in the transplant field to: 1) improve the knowledge and application of best practices in donor/cord selection among network transplant center teams, 2) raise awareness and understanding of CIBMTR and NMDP research findings about donor selection, and 3) increase knowledge of advances in cord blood selection.

In-person conferences and webinars on cord blood selection, best practices and on understanding HLA matching have received outstanding ratings. Participants said the information was helpful and could be applied to their clinical practices. The Advances in Transplantation electronic and print newsletter provides relevant and timely access to the most recent research and publications by summarizing important findings in this area. Subscriptions have grown dramatically and NMDP is looking to build its subscription base (http://www.marlow.org/Physicians/Medical_Education/Medical_Education.aspx). In addition, the newly redeveloped website for CIBMTR, <http://www.cibmtr.org>, provides improved access to relevant publications and research findings.

2.1.5.2 Streamline

Support transplant centers' ability to streamline searches and help patients progress to their transplant efficiently and cost-effectively. Each year, the OPA/SPA develops and introduces new services and enhances its existing educational programs. To help network transplant centers understand how the organization can help their center, NMDP delivers instruction through in-person educational conferences, exhibit booths at conferences, focused group meetings and webinars. Following are some of the educational programs that have helped physicians and their teams adopt and use the key services and resources of the NMDP:

- Custom Search Support, which provides expertise and logistic support for the donor and cord blood search process.
- Referral Outreach, which provides support for transplant centers to educate local referring physicians to improve access.
- HLA Nomenclature Education, which enables transplant centers and other clinicians to adapt their processes and systems to accommodate changes.

2.1.5.3 Care

Influence and enable referring and transplant physicians to provide the best in post-transplant care to their patients. NMDP research with referring physicians showed that referring physicians were uncomfortable with managing their patients' post-transplant care. Some said they refer fewer patients for a transplant because of this issue. A lack of thorough post-transplant care leads to complications and poorer transplant outcomes, which reinforces a physician's negative perceptions and limits future referrals. While NMDP cannot eliminate complications, it can increase physician knowledge of, and therefore comfort with, patient management.

When patient and physician resources are coordinated, this helps ensure that both are better equipped to talk to each other about what care is needed and how to recognize early complications. In the past two years, NMDP developed the Quick Reference Guidelines for referral and post-transplant care, which can be found at <http://www.marlow.org/md-guidelines>, to teach physicians about transplant care for their patients. These resources have been promoted at large medical conferences such as the American Society of Hematology and the BMT Tandem Meetings. The NMDP online Physician Resource Center: <http://www.marlow.org/Physicians> also contains helpful information on post-transplant care, and provides ready access for physicians seeking to learn more. The Advances in Transplantation electronic e-newsletter also routinely communicates the latest advances in post-transplant care information to a growing list of subscribers. The Professional Education team also helped promote a patient version of the post-transplant care guidelines, which is now featured prominently on the CIBMTR Web site.

2.1.6 Develop and Maintain a Website for the Program

The Program's Web site (<http://www.bloodcell.transplant.hrsa.gov>) is an official U.S. Government Web site managed by the Health Resources and Services Administration, U.S. Department of Health & Human Services. It was developed during the summer of 2007 for the C.W. Bill Young Cell Transplantation Program by representatives of the four Program areas and HRSA staff. The site has information for patients, health care providers, and other members of the public about the C.W. Bill Young Cell Transplantation Program, transplant resources, marrow and cord blood donation, and research and outcomes data.