NATIONAL MARROW DONOR PROGRAM® BE THE MATCH®

2012 COUNCIL MEETING

A6: An Information Session Toolbox

Saturday, November 10, 2012

8:00 - 9:15 a.m.

Presented by

Jay Liberatore, BA
Karianta McCaw-Blaise, MBA
Hope Guidry-Groves, BS

Objectives

At the conclusion of this session, the attendee will be able to:

1. Discover existing resources that workup staff can use and assimilate prior to an information session being delivered.
2. Identify two new methods staff can incorporate when educating donors at workup.
3. Name one change you will make during an information session to personalize your delivery.

Conflict of Interest/Financial Disclosure
The Speaker(s) voluntarily disclosed the following pertinent financial relationships and/or conflicts of interest:

- *None – The speaker(s) in this session have disclosed NO conflicts*

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Attendee Signature Date

This signed cover page may be retained in your training files as evidence of your attendance at this session. This document does NOT act as evidence of Professional Continuing Education credits earned.

Information Session Resources

NOTE: An "Information Session Resources" page is being developed and posted to the NMDP Network Website. The resource listed/described below will be link on the page.

Resources for Guiding the Information Session: These resources will help the donor center enrich their information sessions. Donor centers can use these tools to personalize the information session by providing specific data that certain donors may be interested in.

- Donor Consent Forms
- Marrow Information Session Outline & PBSC Information Session Outline
- Be The Match YouTube Channel
- Guidelines for Social Media Sharing

Filgrastim Resources: When workup coordinators understand why PBSCs are facilitated using an IND, filgrastim symptoms and possible risks, you're better able to explain this to the donor.

- General Information on Filgrastim for Donor Center Staff (A00342-Do not share with donor)

**The resources below about PBSC donation, Filgrastim/Neupogen can be selectively shared with donors accustomed to reading and understanding scientific research, and may prove especially useful.

- Amgen/Neupogen Website (This Product information is written with sick patients, not healthy donors in mind. Please explain to donors if this website is shared)
- Suggested Articles PBSC Information (A00194)

HLA Resources: Many donors want to have a better understanding of how and why they were chose as the best match for the recipient. They want HLA explained to them in a way that is easy to understand and allows them to share how special they are with their friends and families.

- Introduction to Basic HLA
- Navigating your Way through HLA
- Navigating your Way through HLA – Module 2
- Seattle Cancer Care Alliance HLA Description
- The Yin & Yang of HLA/ The Yin & Yang of HLA Workbook
- Traditional Perspective on Non-HLA Factors in Donor Search

Disease Resources: These resources allow staff to answer questions about the recipient's disease. Donors want to fully understand how their marrow/stem cells can help the recipient.

- CDC
- Disease Description Sheets
- Mayo Clinic
- Medline Plus
- Merck Manuals
- National Cancer Institute
- National Heart Lung and Blood Institute

Donor/Recipient Timelines: After the information session, the donor will fully understand the steps of the donation process but may want more information on the recipient's time frame. These resources can help explain the stages and timeframes of the transplant process.

- Be The Match - The Transplant Process
- You're a Match Notebook
- You're a Match online Course

Risks of Donation: A donor must fully understand the risks of donation in order to give informed consent. Risks are one of the most important topics discussed during the information session.

- Donor Consent Forms

NMDP Departments: Coordinators can contact these various departments to have their questions answered.

- Donor Advocacy: advocate@nmdp.org Donor Advocacy can assist with donor confidentiality issues, donor/recipient contact issues, donor insurance/disability issues, financial issues, informed consent or any other unusual events.
- Medical Services: dms@nmdp.org The Donor Medical Services Department includes our medical directors and nurse coordinators. They are equipped to handle all questions pertaining to the donor's medical health.
- AC-CC Liaisons: AC-CCliaison@nmdp.org The AC/CC liaison team is able to answer all questions pertaining to the apheresis centers and/or collection centers. They can answer questions about the number of collections a specific AC or CC has facilitated.
- DC Liaisons: DCBMS-DonorCenterLiaisons@nmdp.org The DC liaison team is able to answer or direct questions related to operational efficiencies, support services, and problem solving issues to appropriate departments. Contact your center's assigned Liaison if you need access to a report that donor centers may need related to TDM or monthly statistics.

NMDP Facts & Figures: Many donors want to know what their chances were of being chosen as a match. They want to know more about the NMDP and the number of lives we touch and change.

- NMDP Key Messages, Facts & Figures
- NMDP Report to the Community

Cultural Resources: Each information session is different because each donor is different. One way to have a successful information session is through personalizing the conversation for the donor. Cultural resources can help staff understand some of the differences within cultures.

- Be The Match - website - Translated materials for Registry Members
- African American Marrow Connection - website
- Asians for Miracle Marrow Matches - website
- Inspire Book – Cultural Section
- Promoting Bone Marrow Awareness for the Global Filipino - website
- South Asian Marrow Association of Recruiters - website
- The Icla Da Silva Foundation - website

Laboratory Tests or Drug Information: Many donors may be taking medications or have had tests done that they are unsure of. These resources can help staff learn more about the donor's health.

- Lab Tests Online website
- Physician's Desk Reference online

Recipient Outcomes: Some donors may be interested in understanding what the potential recipient's chances of survival are. This site lists various diseases and corresponding transplant survival rates.

- Be The Match Transplant Outcomes and Trends

Research / Journal Articles: Many donors want to read the research published about past donations. Links to various research/journal articles may prove especially useful for donors accustomed to reading and understanding scientific research.

- Suggested Articles - Marrow Information (A00193)