



NATIONAL MARROW DONOR PROGRAM BE THE MATCH[®]

SHARING OUR PASSION FOR LIFE

COUNCIL MEETING 2013

Post-transplant Communications: Connecting Recipients and Adult Donors

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Financial Disclosures – None

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Learning Objectives

At the end of this session, you'll be able to:

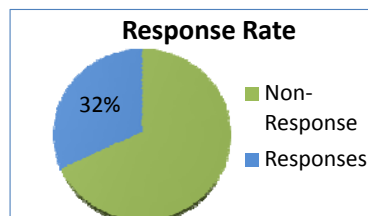
- Summarize National Marrow Donor Program's (NMDP) post-transplant communication satisfaction survey findings and implications.
- Describe the role of the NMDP in facilitating post-transplant communications between recipients and donors.
- Apply policies, standard procedures, and best practices in communication with donors and recipients.

Agenda

- Survey results
- Anonymous correspondence
 - Discussion 1
- Recipient updates
 - Discussion 2
- Exchange of consents
 - Discussion 3

Post-transplant communications satisfaction survey

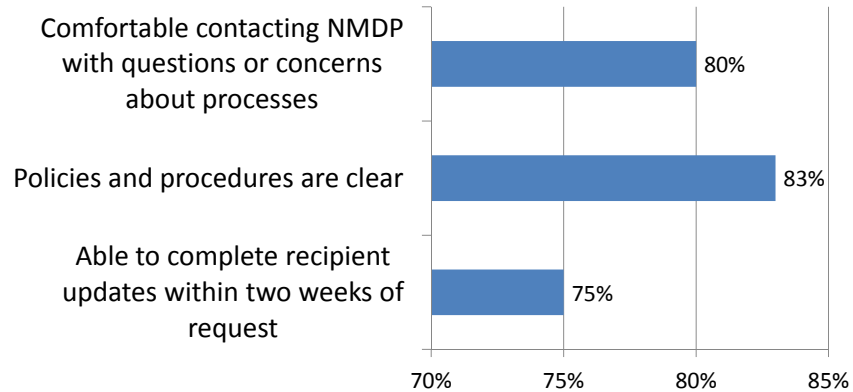
- Assessed baseline satisfaction
 - 1,556 online surveys
 - All TC & DC partners (U.S. & international)



- Survey will be repeated annually

What we heard from TCs

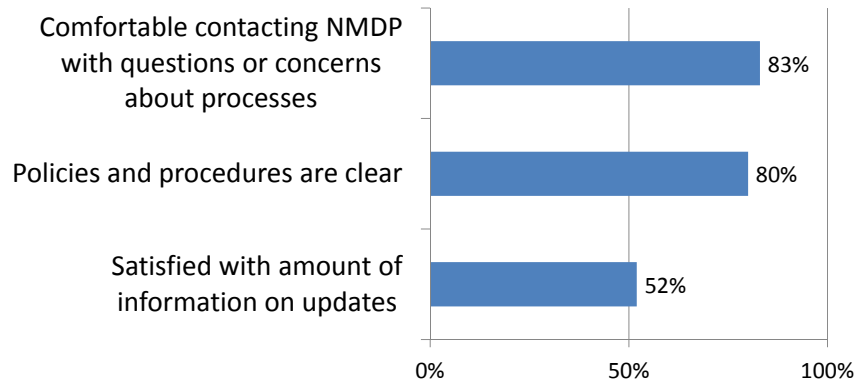
(N=285)



– Common theme: improvements due to dedicated, single point of contact at NMDP

What we heard from DCs

(N=186)



– Common theme: significant improvements made with restructured function

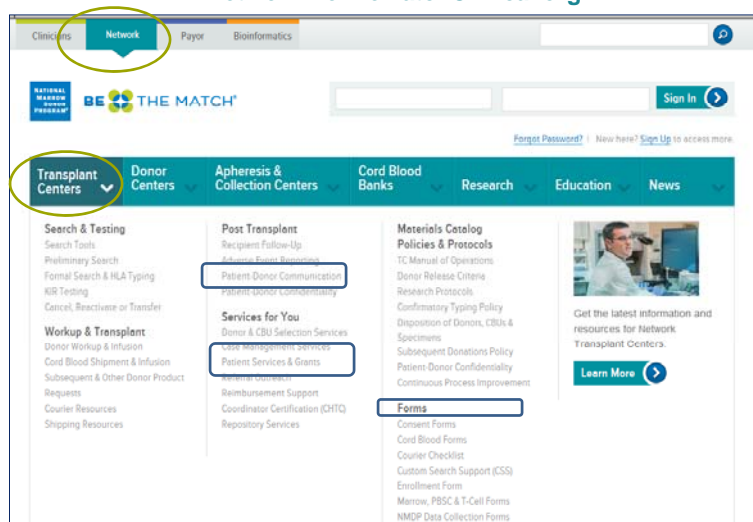
Opportunities for improvement

We also heard:

- There are issues on both sides of the recipient update process
- You'd like to know your requests have been received
- You don't always get a response to your request
- More training is needed in this area

Find Post-Transplant Communications and Forms

Network.BeTheMatchClinical.org



Post-Transplant Communications Policies

Network.BeTheMatchClinical.org
(Network website)
chapter 11 of TC/DC Manual of Operations

Policies Regarding Post-Transplant Communications between Donors and Recipients							
Country	Center #	Center Name	City	Anonymous Contact Allowed	Exchange of Gifts Allowed	Direct Contact Allowed	NMDP Recipient Updates (Form 180 series) Required
Argentina	333	National Registry of CPH Donors	Buenos Aires	YES	NO	Yes – one year post TX	Not Required; will accept requests from NMDP
Armenia	330	American Bone Marrow Donor Registry	Yerevan	YES – through Registry only	YES – if anonymous and screened by Registry	NO	Not Required; will accept requests from NMDP
Australia	553	Australian Bone Marrow Donor Registry	Sydney	YES	YES – if anonymous	YES – but discouraged. No waiting period but generally discouraged. Must have donor and recipient consent and some anonymous contact.	Not Required; will accept requests from NMDP
Austria	567	Austrian Bone Marrow Donors	Vienna	Yes – through Registry only	NO	Yes after three years. Contact is not encouraged. Patient must instigate the request for direct contact.	Not Required; will accept requests from NMDP

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Anonymous correspondence

- Setting expectations
 - ***Post-Transplant Communications Policies***
 - Length of time to complete exchange
 - Define anonymous
- What is acceptable to share?
 - **BeTheMatch.org** has information with examples of what can and can't share
 - Country is *not* considered personally identifying information – okay to share

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The exchange

- Post-transplant only
 - Cannot be sent with courier
- Three screening steps:
 1. Initiating center
 2. Be The Match Patient Services
 3. Receiving center (has final say)
- Recipient death
 - Names still cannot be shared without consent

Discussion 1:Correspondence

- Select a note-taker
- Discussion questions:
 1. Do you encourage your recipients/donors to send letters/cards/gifts – why or why not?
 2. How and when do you discuss anonymous correspondence with donor/recipient?
 3. Best practices for managing this process?
 4. Suggestions for improvements?

Recipient update overview

- They are important
 - CIBMTR Observational Database
 - Feedback to donors
- They are required of domestic TCs
 - Manual of Operations, Chapter 11
 - Form 180 series
- They are not required of international TCs
 - May provide upon request (100 days)
- **Post-Transplant Communications Policies**

Donor satisfaction survey

- Number 1 opportunity for improvement is recipient updates
 - Comments indicate unrealistic expectations
- DC's responsibility to set expectations
 - Chapter 11 of DC Manual of Operations
 - Reporting frequency (grace period)
 - **Post-Transplant Communications Policies**

Form 180 series - timelines

Form name	Earliest date	Due date	Expired date
F180 (30 day)	+25	+45	+149
F183 (6 mo)	+150	+210	+329
F184 (1 year)	+330	+395	+545

100% on-time submission expected.

F180s are not required after a cord transplant.

Submitting required updates

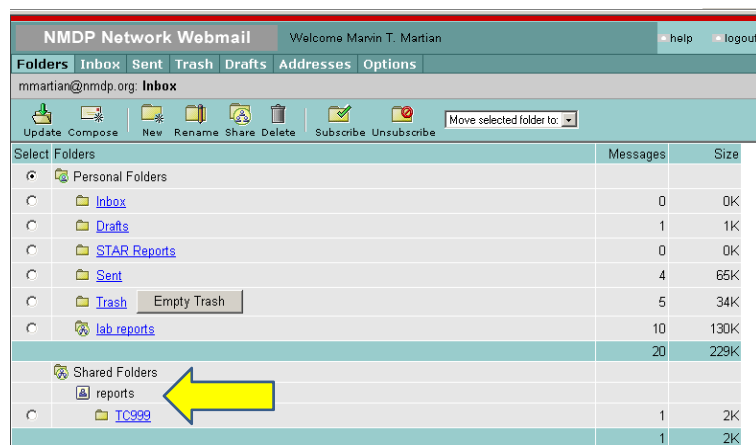
- Reminder in your work flow management report that update is due
- Submit via
 - *FormsNet*
 - *or Print form and send to Registry*
 - Email: scanform@nmdp.org, or
 - Fax: 1 (612) 627-5895
- Once updated in the system, DCs are automatically notified

Recipient death notifications

- Use CIBMTR Form 2900 or 2450
 - Stops the F180 series
 - Notifications are sent to all stakeholders (CIBMTR, DC, Patient Services, etc.)
 - If you report it only on the F180 series, F180 reminders will continue - *and notifications are not sent*

Finding the updates & notifications

FormsNet and Webmail reports



After one year post-transplant

- 180s are no longer required....
 - *But I still want updates!*
 - *So why are you asking me for updates?*
- International requests
- We will continue to request updates for you,
 - If consent for donors/recipients to have direct contact is not allowed, or was declined
- **Post-Transplant Communications Policies**

Discussion 2: Recipient updates

- Select a note-taker
- Discussion questions:
 1. *DCs - how do you set expectations about recipient updates with your donor?*
 2. *TCs - what is your system for submitting recipient updates?*
 3. *DCs - what is your system for monitoring receipt of recipient updates?*
 4. *TCs - how do you manage requests for recipient updates after one year?*

Consent for direct contact

- Counseling donors and recipients
 - Risks/benefits
 - Response time
 - **Post-Transplant Communications Policies**
- Legibility
 - Typed or Adobe Pro, or send email to clarify
- Recipient death
 - Waiting period may be waived
 - Confidentiality rules still apply

Discussion 3: Consent for direct contact

- Select a note-taker
- Discussion questions:
 1. *How do you manage requests for consent?*
 2. *NMDP has a two-step consent process:*
 - *Request for consent initiated first*
 - *Consent forms sent in if the other side consents*
- a) *Does this process work well for your center?*
- b) *Are there ways to improve the process?*

Questions

Network.BeTheMatchClinical.org

Post-Transplant Communications Policies

Contact us at: connections@nmdp.org