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)

- Comfortable contacting NMDP with questions or concerns about processes: 80%
- Policies and procedures are clear: 83%
- Able to complete recipient updates within two weeks of request: 75%

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

What we heard from DCs
(N=186)

- Comfortable contacting NMDP with questions or concerns about processes: 83%
- Policies and procedures are clear: 80%
- Satisfied with amount of information on updates: 52%

-- 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
*Post-Transplant Communications Policies*

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

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

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
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

<table>
<thead>
<tr>
<th>Form name</th>
<th>Earliest date</th>
<th>Due date</th>
<th>Expired date</th>
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<tbody>
<tr>
<td>F180 (30 day)</td>
<td>+25</td>
<td>+45</td>
<td>+149</td>
</tr>
<tr>
<td>F183 (6 mo)</td>
<td>+150</td>
<td>+210</td>
<td>+329</td>
</tr>
<tr>
<td>F184 (1 year)</td>
<td>+330</td>
<td>+395</td>
<td>+545</td>
</tr>
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100% on-time submission expected.

F180s are not required after a cord transplant.

Submitting required updates

- Reminder in your workflow 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/recipient 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