What’s New in Data Management?
Presented by: Marie Matlack
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There are no conflicts of interest to disclose.
WHAT'S NEW
SCOOBY-DOO?
CIBMTR CPI Changes

May 2018

- CPI Probation Warning Status will be eliminated
  - Good Standing
  - First Warning: First failure
  - Probation: Second consecutive failure
  - Suspension: Third consecutive failure
- Study forms will now be included in CPI
  - Study form numbers beginning with 25XX

September 2018

- Forms in QRY, ERR, and MOD status will be included in CPI
- CIBMTR will be mindful of the volume and timing of adding queries to forms
Center Forms Due

Recipient Center Forms Due

Centers:
- 99999 FORMSNET TEST RESEARCH CENTER

Status Codes:
- DUE Form has not started
- ERR Form has errors
- SVD Form was saved
- MOD Form was modified

Forms:
- 2000 Recipient Baseline Data
- 2004 Infectious Disease Markers
- 2005 Confirmation of HLA Typing
- 2006 Hematopoietic Cellular Transplant (HCT) Infusion

Date Type:
- Earliest Completion Date

Start Data: YYYY-MM-DD

CPI Period: 
End Date: YYYY-MM-DD

Infusion Type:

Search
Generate CPI Lists

- Displays due forms
- Capability to directly export to Excel
International Center Specific Analysis

- Centers can join for 2019
- Contact your CRC
- Need to register all your patients
What next for Forms Revision?

• Spring – starting revisions
  – 2400 & 2000
  – 2006

• Releasing a new viral infection form in spring

• Updating the transfer form and process to accommodate cellular therapies

• To propose changes or volunteer to participate in revision committee
  – cibmtrformfeedback@nmdp.org
Veno-occlusive Disease (VOD) / Sinusoidal Obstruction Syndrome (SOS) Supplemental (Form 2553)

• Form needs to be fully complete
• Will not get reimbursed if there is missing data
• eLearning module is in Online Training
On the Horizon

- WMDA GRID Project
- Global Registration Identifier for Donors (GRID)
- Create a standard, consistent system for issuing organizations to assign a globally unique identifier to potential unrelated HPC donors
Reporting Related HCTs
NMDP Facilitated Related Donor Work-ups

• Typically, NMDP has been known as an unrelated donor registry.

• After multiple requests to help transplant centers with a related donor, NMDP started offering the service of facilitating related donor work-ups on behalf of the transplant centers

• Related Donor Services
Overcome barriers to donation

Related Donor Services

Reduce staff time on related transplants

Provide related donor services and support
Adding the Recipient NMDP ID

CIBMTR Assignment Form 2804
Assign CRID
### CIBMTR Research ID Assignment Form

#### Key Fields

- **CIBMTR Center Number:** <Select Center>

#### Demographics

**Questions: 1 - 17**

1. **First name:** (patient) [One hundred characters allowed]
2. **Last name:** (patient) [One hundred characters allowed]
3. **Date of birth:** YYYY-MM-DD
4. **Location of birth:**
   - **Country:**
   - **State:**
   - **City:** [One hundred characters allowed]
5. **Sex:**
   - Male
   - Female
Search/Edit CRID
Reporting a related HCT facilitated by NMDP

* Need to report as a related HCT

* Enter donor data into related section of form

* It may be confusing because the Related donor is assigned a NMDP donor ID
Donor Information on Pre-TED Form 2400

31. Specify donor:
- Related donor

32. NMDP donor ID:

33. NMDP donor ID:

34. Non-NMDP unrelated donor ID (not applicable for related donors):

35. Non-NMDP cord blood unit ID (include related and autologous CBUs):

36. Is the CBU ID also the ISBT DIN number?
- Yes
- No

37. Specify the ISBT DIN number:

38. Registry or UCB Bank ID:

39. Specify other Registry or UCB Bank:

40. Specify the related donor type:
- Syngeneic (monozygotic twin)
- HLA-identical sibling (may include non- monozygotic twin)
- HLA-matched other relative
- HLA-mismatched relative

41. Date of birth:
- Known
- Unknown
New e-Learning Module
Haploidentical HCT

- Allogeneic transplant
- It uses healthy, blood-forming cells from a half-matched donor to replace the unhealthy ones.
- Donor is typically a family member.
How to Report Haploidentical HCTs

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>31</td>
<td>Specify donor: Related donor ▼</td>
</tr>
<tr>
<td>32</td>
<td>NMDP cord blood unit ID: Zero decimal places allowed</td>
</tr>
<tr>
<td>33</td>
<td>NMDP donor ID: Zero decimal places allowed</td>
</tr>
<tr>
<td>34</td>
<td>Non-NMDP unrelated donor ID: (not applicable for related donors) Thirty characters allowed</td>
</tr>
<tr>
<td>35</td>
<td>Non-NMDP cord blood unit ID: (include related and autologous CBUs) Thirty characters allowed</td>
</tr>
<tr>
<td>36</td>
<td>Is the CBU ID also the ISBT DIN number? □ Yes □ No</td>
</tr>
<tr>
<td>37</td>
<td>Specify the ISBT DIN number: Sixteen characters allowed</td>
</tr>
<tr>
<td>38</td>
<td>Registry or UCB Bank ID ▼</td>
</tr>
<tr>
<td>39</td>
<td>Specify other Registry or UCB Bank: One hundred characters allowed</td>
</tr>
<tr>
<td>40</td>
<td>Specify the related donor type: □ Syngeneic (monozygotic twin) □ HLA-identical sibling (may include non-monozygotic twin) □ HLA-matched other relative □ HLA-mismatched relative</td>
</tr>
</tbody>
</table>

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CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH
Forms Editable in FormsNet 3

- Previous versions of the most commonly used forms that were in FormsNet 2 will be editable in FormsNet 3
- CIBMTR can place queries in FormsNet and avoid paper error corrections
- An exception would be forms submitted via EBMT
  - Corrections need to be sent to EBMT
Forms Grid

- Edit icon or PDF icon
  - Forms with a PDF icon still require error correction forms
General Notes

- When making updates to form, **Reprocess** it
- If track changes, contact your CRC
- Subsequent transplant – report in real time
- Attach pathology report for any new malignancy
- Attach a lab report for chimerism tests
- When to use the consent status of “Not Approached”
Confidentiality

• Communication
  – Do not include patient identifiers
    (i.e., First or last name)
• Attachments (FormsNet or paper)
  – De-identify reports
    (i.e. medical record number)

Remember to put the CRID on each page
FACT & CPI

• Keep a copy (electronic or paper) of your CPI letter for future FACT audits
• Contact Monique Ammi (mammi@nmdp.org)
Request for Center Updates

- Verify contact information
- Verify Medical Director
- Verify reporting (HCT type, CRF or TED)
- Updates to:  
  cibmtr-centermaintenance@nmdp.org
Thank you so very much.