2132: Chediak-Higashi Syndrome Post-HSCT Data

To be completed in conjunction with a Form 2100 – 100 Days Post-HSCT Data, Form 2200 – Six Months to Two Years Post-HSCT Data, or Form 2300 – Yearly Follow-Up for Greater Than Two Years Post-HSCT Data. Information reported here should reflect the date of last contact as reported in the post-HSCT data collection form, or immediately prior to death.

Key Fields

Sequence Number: ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________
ELSE GOTO Date Received:

Date Received: ___ YYYY ___ MM ___ DD
ELSE GOTO CIBMTR Center Number

CIBMTR Center Number ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________
ELSE GOTO CIBMTR Recipient ID:

CIBMTR Recipient ID: ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________ ___________
ELSE GOTO Today's Date:

Today's Date: ___ YYYY ___ MM ___ DD
ELSE GOTO Date of HSCT for which this form is being completed:

Date of HSCT for which this form is being completed: ___ YYYY ___ MM ___ DD
ELSE GOTO Autologous

HSCT type: (check all that apply)
☐ Autologous
ELSE GOTO Allogeneic, unrelated

☐ Allogeneic, unrelated
ELSE GOTO Allogeneic, related

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Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).
1. What is the date the recipient’s current status was evaluated? ____________
   ELSE GOTO (1) What is the date the recipient’s current status was evaluated?

 ELSE GOTO (2) What is the status of any clinical features of Chediak-Higashi Syndrome at the date of last contact for this report?

2. What is the status of any clinical features of Chediak-Higashi Syndrome at the date of last contact for this report?
   O absent
IF (2) What is the status of any clinical features of Chediak-Higashi Syndrome at the date of last contact for this report?:

- **absent**

THEN GOTO (15) What was the status of any neurologic symptoms of Chediak-Higashi Syndrome since the date of the last report?

ELSE GOTO (3) Date of recurrence:

<table>
<thead>
<tr>
<th>Date of recurrence:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>O</strong> known</td>
</tr>
<tr>
<td><strong>O</strong> unknown</td>
</tr>
</tbody>
</table>

IF (3) Date of recurrence::= known

THEN GOTO (4) Specify:

ELSE GOTO (5) Anemia (Hb < 10g/dL)

4 Specify: __ __ __ __ __ __ __ __ __ __ __

□ Date of recurrence previously reported

ELSE GOTO Date previously reported

Specify clinical feature(s) present:

5 Anemia (Hb < 10g/dL)

- **O** present
- **O** absent
- **O** unknown

ELSE GOTO (6) Bleeding diathesis

6 Bleeding diathesis

- **O** present
- **O** absent
- **O** unknown

ELSE GOTO (7) Hepatomegaly

7 Hepatomegaly

- **O** present
- **O** absent
- **O** unknown

ELSE GOTO (8) Leukocyte granules

8 Leukocyte granules

- **O** present
- **O** absent
- **O** unknown

ELSE GOTO (9) Neutropenia (ANC < 1 x 10⁹/L)

9 Neutropenia (ANC < 1 x 10⁹/L)

- **O** present
- **O** absent
CIBMTR Center Number: _______ _______ _______ CIBMTR Recipient ID: _______ _______ _______ _______ _______ _______ _______ 

Recurrence of infections

10 Recurrent infections
   ○ present
   ○ absent
   ○ unknown

Splenomegaly

11 Splenomegaly
   ○ present
   ○ absent
   ○ unknown

Thrombocytopenia (< 100 x 10^9/L)

12 Thrombocytopenia (< 100 x 10^9/L)
   ○ present
   ○ absent
   ○ unknown

Other

13 Other
   ○ present
   ○ absent
   ○ unknown

IF (13) Other:= present
THEN GOTO (14) Specify:
ELSE GOTO (15) What was the status of any neurologic symptoms of Chediak-Higashi Syndrome since the date of the last report?

Specify: __________________________

What was the status of any neurologic symptoms of Chediak-Higashi Syndrome since the date of the last report?

15 What was the status of any neurologic symptoms of Chediak-Higashi Syndrome since the date of the last report?
   ○ absent
   ○ present
   ○ unknown

IF (15) What was the status of any neurologic symptoms of Chediak-Higashi Syndrome since the date of the last report?:= present
THEN GOTO (16) Were neurologic symptoms present prior to the HSCT?
ELSE GOTO (18) Did the recipient develop features of accelerated phase since the date of the last report?

Were neurologic symptoms present prior to the HSCT?

16 Were neurologic symptoms present prior to the HSCT?
   ○ yes
   ○ no (symptoms are newly developed)
   ○ unknown

IF (16) Were neurologic symptoms present prior to the HSCT?:= yes
THEN GOTO (17) What is the current status of neurologic dysfunction compared to prior to the HSCT?
ELSE GOTO (18) Did the recipient develop features of accelerated phase since the date of the last report?

What is the current status of neurologic dysfunction compared to prior to the HSCT?
17 What is the current status of neurologic dysfunction compared to prior to the HSCT?
- O improved
- O unchanged
- O worsened
- O unknown

ELSE GOTO (18) Did the recipient develop features of accelerated phase since the date of the last report?

18 Did the recipient develop features of accelerated phase since the date of the last report?
- O yes
- O no

IF (18) Did the recipient develop features of accelerated phase since the date of the last report?:= yes
THEN GOTO (19) chs_post_dev_acc_dte
ELSE GOTO (20) Did the recipient have magnetic resonance imaging (MRI) of the brain since the date of the last report?

19 □ Date of diagnosis previously reported
- O YYYY
- O MM
- O DD

ELSE GOTO Date of diagnosis previously reported
ELSE GOTO (20) Did the recipient have magnetic resonance imaging (MRI) of the brain since the date of the last report?

20 Did the recipient have magnetic resonance imaging (MRI) of the brain since the date of the last report?
- O yes
- O no
- O unknown

IF (20) Did the recipient have magnetic resonance imaging (MRI) of the brain since the date of the last report?:= yes
THEN GOTO (21) Specify MRI findings:
ELSE GOTO (23) Cytotoxic T-cell activity

21 Specify MRI findings: __________________________

ELSE GOTO (22) Is a copy of the MRI report attached?

22 Is a copy of the MRI report attached?
- O yes
- O no

ELSE GOTO (23) Cytotoxic T-cell activity

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THEN GOTO (25) Granulocyte chemotaxis
ELSE GOTO (24) Date of test

24    YYYY MM DD
IF (24) Date of test:= EXISTS
THEN GOTO (25) Granulocyte chemotaxis
ELSE GOTO Date unknown

25 Granulocyte chemotaxis
   O Absent
   O Decreased
   O Normal
   O Increased
   O Not Tested
IF (25) Granulocyte chemotaxis:= Not Tested
THEN GOTO (27) IgG
ELSE GOTO (26) Date of test

26    YYYY MM DD
ELSE GOTO Date unknown

27 IgG
   O Absent
   O Decreased
   O Normal
   O Increased
   O Not Tested
IF (27) IgG:= Not Tested
THEN GOTO (29) IgA
ELSE GOTO (28) Date of test

28    YYYY MM DD
ELSE GOTO Date unknown

29 IgA
   O Absent
   O Decreased
   O Normal
   O Increased
   O Not Tested
IF (29) IgA:= Not Tested
THEN GOTO (31) IgM
ELSE GOTO (30) Date of test

30 □ Date of IgA test unknown
□ YYYY MM DD
ELSE GOTO Date unknown
ELSE GOTO (31) IgM

31 IgM
☐ Absent
☐ Decreased
☐ Normal
☐ Increased
☐ Not Tested
IF (31) IgM:= Not Tested
THEN GOTO (33) IgE
ELSE GOTO (32) Date of test

32 □ Date of IgM test unknown
□ YYYY MM DD
ELSE GOTO Date unknown
ELSE GOTO (33) IgE

33 IgE
☐ Absent
☐ Decreased
☐ Normal
☐ Increased
☐ Not Tested
IF (33) IgE:= Not Tested
THEN GOTO (35) Natural killer cell activity
ELSE GOTO (34) Date of test

34 □ Date of IgE test unknown
□ YYYY MM DD
ELSE GOTO Date unknown
ELSE GOTO (35) Natural killer cell activity

35 Natural killer cell activity
☐ Absent
☐ Decreased
☐ Normal
☐ Increased
☐ Not Tested
IF (35) Natural killer cell activity:= Not Tested
THEN GOTO (37) T-cell numbers / subsets
ELSE GOTO (36) Date of test
### ERROR CORRECTION FORM

**CIBMTR Center Number:** _______ __________

**CIBMTR Recipient ID:** _______ __________

Today’s Date:

<table>
<thead>
<tr>
<th>Month</th>
<th>Day</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Infusion Date:

<table>
<thead>
<tr>
<th>Month</th>
<th>Day</th>
<th>Year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

**CIBMTR Center Number:** _______ __________

<table>
<thead>
<tr>
<th>36</th>
<th>yyyy</th>
<th>mm</th>
<th>dd</th>
</tr>
</thead>
</table>

☐ Date of Natural killer cell activity test unknown

ELSE GOTO Date unknown

ELSE GOTO (37) T-cell numbers / subsets

<table>
<thead>
<tr>
<th>37</th>
<th>T-cell numbers / subsets</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>Absent</td>
</tr>
<tr>
<td>O</td>
<td>Decreased</td>
</tr>
<tr>
<td>O</td>
<td>Normal</td>
</tr>
<tr>
<td>O</td>
<td>Increased</td>
</tr>
<tr>
<td>O</td>
<td>Not Tested</td>
</tr>
</tbody>
</table>

IF (37) T-cell numbers / subsets:: Not Tested

THEN GOTO (39) T-cell function

ELSE GOTO (38) Date of test

<table>
<thead>
<tr>
<th>38</th>
<th>yyyy</th>
<th>mm</th>
<th>dd</th>
</tr>
</thead>
</table>

☐ Date of T-cell numbers/subsets unknown

ELSE GOTO Date unknown

ELSE GOTO (39) T-cell function

<table>
<thead>
<tr>
<th>39</th>
<th>T-cell function</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>Absent</td>
</tr>
<tr>
<td>O</td>
<td>Decreased</td>
</tr>
<tr>
<td>O</td>
<td>Normal</td>
</tr>
<tr>
<td>O</td>
<td>Increased</td>
</tr>
<tr>
<td>O</td>
<td>Not Tested</td>
</tr>
</tbody>
</table>

IF (39) T-cell function:: Not Tested

THEN GOTO (41) Did the recipient receive IVIG infusions within 2 months prior to the above immunoglobulin measurement?

ELSE GOTO (40) Date of test

<table>
<thead>
<tr>
<th>40</th>
<th>yyyy</th>
<th>mm</th>
<th>dd</th>
</tr>
</thead>
</table>

☐ Date of T-cell function test unknown

ELSE GOTO Date unknown

ELSE GOTO (41) Did the recipient receive IVIG infusions within 2 months prior to the above immunoglobulin measurement?

<table>
<thead>
<tr>
<th>41</th>
<th>Did the recipient receive IVIG infusions within 2 months prior to the above immunoglobulin measurement?</th>
</tr>
</thead>
<tbody>
<tr>
<td>O</td>
<td>yes</td>
</tr>
<tr>
<td>O</td>
<td>no</td>
</tr>
<tr>
<td>O</td>
<td>unknown</td>
</tr>
</tbody>
</table>

ELSE GOTO First name

<table>
<thead>
<tr>
<th>First Name:</th>
<th>Last Name:</th>
</tr>
</thead>
</table>

ELSE GOTO Last name

ELSE GOTO Phone number:

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## ERROR CORRECTION FORM

<table>
<thead>
<tr>
<th>Sequence Number:</th>
<th>CIBMTR Recipient ID:</th>
<th>Initials:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Today's Date:</th>
<th>Infusion Date:</th>
<th>CIBMTR Center Number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month</td>
<td>Day</td>
<td>Year</td>
</tr>
<tr>
<td>Month</td>
<td>Day</td>
<td>Year</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CIBMTR Center Number:</th>
<th>CIBMTR Recipient ID:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone number:</td>
<td>Fax number:</td>
</tr>
</tbody>
</table>

ELSE GOTO Fax number: ELSE GOTO E-mail address:

E-mail address:  
ELSE GOTO End of Form

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