CIBMTR® CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Instructions for Aplastic Anemia Post-HSCT Data (Form 2128)

This section of the CIBMTR Forms Instruction Manual is intended to be a resource for completing the Aplastic Anemia Post-HSCT Data Form.

E-mail comments regarding the content of the CIBMTR Forms Instruction Manual to: CIBMTRFormsManualComments@nmdp.org. Comments will be considered for future manual updates and revisions. For questions that require an immediate response, please contact your transplant center's CIBMTR liaison.

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Aplastic Anemia Post-HSCT Data

Aplastic Anemia is a disease in which the bone marrow does not produce enough red blood cells, white blood cells, or platelets for the body. The disease can be idiopathic or can be caused by environmental exposure, pharmaceutical and drug exposure, or exposure to viral hepatitis. Symptoms of aplastic anemia include, but are not limited to pallor, weakness, frequent infection, and/or easy bruising.

The Aplastic Anemia Post-HSCT Data Form is one of the Comprehensive Report Forms. This form captures aplastic anemia-specific post-HSCT disease assessment data for the reporting period.

This form must be completed for all recipients whose primary disease, as reported on Form 2000 question 9, is severe aplastic anemia, paroxysmal nocturnal hemoglobinuria, or one of the following inherited abnormalities of erythrocyte differentiation or function: Shwachman-Diamond syndrome, Diamond-Blackfan anemia (pure red cell aplasia), or other constitutional anemia. Fanconi Anemia and Sickle Cell Anemia each have their own forms to complete (Forms 2129 and 2130, respectively).

The Aplastic Anemia Post-HSCT Data (Form 2128) must be completed in conjunction with each Post-HSCT follow-up form completed (Forms 2100, 2200, and 2300). Form 2128 is designed to capture specific data occurring within the timeframe of each reporting period (e.g., between day 0 and day 100 for Form 2100, between day 100 and the six-month date of contact for Form 2200 Six-Month follow-up, between the date of contact for the six-month follow-up Form 2200 and the date of contact for the one-year follow up Form 2200, etc).

Key Fields

Accuracy of the Key Fields is essential for ensuring that:

- Data are being reported for the correct recipient.
- Transplant centers have access to their data.
- Data are being shared with the correct donor center, cord blood bank, cooperative registry, or other agency.

For instructions regarding the completion of the Key Fields, see Appendix K. Key fields include all fields listed in the box found in the upper right-hand corner of the first page of the paper form, or on the "key page" in the FormsNet™2 application.

Disease Assessment at the Time of Assessment for This Reporting Period

Question 1: Was the recipient red blood cell (RBC) transfusion independent since the date of the last report?
Indicate if the recipient was RBC transfusion independent since the date of the last report. A general guideline for RBC transfusion independence is that RBC transfusions have not been required for four or more weeks.

Some discretion may be required if the recipient received a transfusion for a surgical procedure or other reason. If a recipient received an RBC transfusion for a procedure and would otherwise be transfusion independent, the recipient may still be reported as being transfusion independent.

If the recipient was RBC transfusion independent since the date of the last report, select "yes" and continue with question 3.

If the recipient was not RBC transfusion independent since the date of the last report, select "no" and continue with question 2.

If it is not known if the recipient was RBC transfusion independent since the date of the last report, select "unknown" and continue with question 3.

Question 2: Date of the most recent RBC transfusion:
Indicate the date of the most recent RBC transfusion.

If the recipient was RBC transfusion independent for ≥ one month, but subsequently experienced a decline in RBCs and required transfusions, record the date of the last RBC transfusion before the date of decline.

If the date reported on question 2 is more than one month prior to the date of contact, evaluate if the recipient is RBC transfusion independent.

Question 3: Was the recipient platelet transfusion independent since the date of the last report?
Indicate if the recipient was platelet transfusion independent since the date of the last report. A general guideline for platelet transfusion independence is that platelet transfusions have not been required for seven or more days.

If the recipient was platelet transfusion independent since the date of the last report, select “yes” and continue with question 5.

If the recipient was not platelet transfusion independent since the date of the last report, select “no” and continue with question 4.

If it is unknown if the recipient was platelet transfusion independent since the date of the last report, select “unknown” and continue with question 5.

If the recipient was never dependent on platelet transfusions or if this question is not applicable, select “not applicable/never dependent” and continue with question 5.

Question 4: Date of the most recent platelet transfusion:
Indicate the date of the most recent platelet transfusion.

If the recipient was platelet transfusion independent for ≥ 14 days but subsequently experienced a decline in platelets and required transfusions, record the date of the last platelet transfusion before the date of decline.

If the date reported on question 4 is more than seven days prior to the date of contact, evaluate if the recipient is platelet transfusion independent.

Question 5: Specify reticulocyte level (uncorrected):
Indicate whether the uncorrected reticulocyte count in the blood is “known” or “not known/transfused” since the date of last report. If the reticulocyte count was assessed multiple times during the reporting period, report the results of the latest reticulocyte count. If “known,” report the value documented on the laboratory report.

If the recipient had an RBC transfusion within 30 days prior to the latest reticulocyte count, select “not known/transfused” and do not report a value.

Report the absolute value of reticulocytes in __ x 10^9/L. Do not report a percentage, the corrected reticulocyte count, or the reticulocyte production index.

Question 6: Signed:
The person completing the form must sign the form; print his/her name; and provide a phone number, fax number, and e-mail address where he/she can be reached.