Legend: update addition

Recipient Death Data

Registry Use Only

Sequence Number:

Date Received:

OMB No: 0915-0310
Expiration Date: 10/31/2022

Public Burden Statement: The purpose of the data collection is to fulfill the legislative mandate to establish and maintain a standardized database of allogeneic marrow and cord blood transplants performed in the United States or using a donor from the United States. The data collected also meets the C.W. Bill Young Cell Transplantation Program requirements to provide relevant scientific information not containing individually identifiable information available to the public in the form of summaries and data sets. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. The OMB control number for this information collection is 0915-0310 and it is valid until 10/31/2022. This information collection is voluntary under The Stem Cell Therapeutic and Research Act of 2005, Public Law (Pub. L.) 109–129, as amended by the Stem Cell Therapeutic and Research Reauthorization Act of 2010, Public Law 111–264 (the Act) and the Stem Cell Therapeutic and Research Reauthorization Act of 2015, Public Law 114-104. Public reporting burden for this collection of information is estimated to average 0.05 hours per response, including the time for reviewing instructions, searching existing data sources, and completing and reviewing the collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to HRSA Reports Clearance Officer, 5600 Fishers Lane, Room 14N136B, Rockville, Maryland, 20857 or paperwork@hrsa.gov.

CIBMTR Center Number: ___ ___ ___ ___ ___

CIBMTR Research ID: ___ ___ ___ ___ ___ ___ ___ ___ ___ ___

Event date: ___ ___ ___ ___ — ___ ___ — ___ ___
YYYY MM DD

Copyright © 2021 National Marrow Donor Program and The Medical College of Wisconsin, Inc. All rights reserved.

Recipient Death

1. Date of death: ___ ___ ___ ___ — ___ ___ — ___ ___ (YYYY MM DD) ☐ Date estimated

2. Was cause of death confirmed by autopsy?
   - ☐ Yes – ***Go to question 3.***
   - ☐ Autopsy pending ***– Go to question 4.***
   - ☐ No – ***Go to question 4.***
   - ☐ Unknown – ***Go to question 4.***

   3. Was documentation submitted to the CIBMTR? *(autopsy report)*
      - ☐ Yes
      - ☐ No

4. Primary cause of death
   - ☐ Recurrence / persistence / progression of disease for which the infusion was performed ***– Go to question 6.***
   - ☐ Acute GVHD ***– Go to question 6.***
   - ☐ Chronic GVHD ***– Go to question 6.***
   - ☐ Graft rejection or failure ***– Go to question 6.***
   - ☐ Cytokine release syndrome ***– Go to question 6.***

   Hemorrhage
   - ☐ Diffuse alveolar hemorrhage (DAH) ***– Go to question 6.***
   - ☐ Gastrointestinal hemorrhage ***– Go to question 6.***
   - ☐ Hemorrhagic cystitis ***– Go to question 6.***
   - ☐ Intracranial hemorrhage ***– Go to question 6.***
   - ☐ Pulmonary hemorrhage ***– Go to question 6.***
   - ☐ Other hemorrhage – ***Go to question 5.***

   Infection
   - ☐ Bacterial infection ***– Go to question 6.***
   - ☐ COVID-19 (SARS-CoV-2) ***– Go to question 6.***
   - ☐ Fungal infection ***– Go to question 6.***
   - ☐ Infection, organism not identified ***– Go to question 6.***
   - ☐ Protozoal infection ***– Go to question 6.***
   - ☐ Viral infection ***– Go to question 6.***
   - ☐ Other infection – ***Go to question 5.***

Copyright © 2021 National Marrow Donor Program and The Medical College of Wisconsin, Inc. All rights reserved.

Malignancy

- ☐ New malignancy *(post-infusion)* ***– Go to question 6.***
- ☐ Prior malignancy *(malignancy initially diagnosed prior to infusion, other than the malignancy for which the infusion was performed)* ***– Go to question 6.***

Organ failure (not due to GVHD or infection)

- ☐ Cardiac failure ***– Go to question 6.***
- ☐ Central nervous system (CNS) failure ***– Go to question 6.***
- ☐ Gastrointestinal (GI) failure *(not liver)* ***– Go to question 6.***
- ☐ Liver failure (not VOD) ***– Go to question 6.***
- ☐ Multiple organ failure – ***Go to question 5.***
- ☐ Pulmonary failure***– Go to question 6.***
- ☐ Renal failure ***– Go to question 6.***
- ☐ Veno-occlusive disease (VOD) / sinusoidal obstruction syndrome (SOS) ***– Go to question 6.***
- ☐ Other organ failure – ***Go to question 5.***

Pulmonary

- ☐ Acute respiratory distress syndrome (ARDS) *(other than IPS)* ***– Go to question 6.***
- ☐ Diffuse alveolar damage *(without hemorrhage)* ***– Go to question 6.***
- ☐ Idiopathic pneumonia syndrome (IPS) ***– Go to question 6.***
- ☐ Pneumonitis due to Cytomegalovirus (CMV) ***– Go to question 6.***
- ☐ Pneumonitis due to other virus ***– Go to question 6.***
- ☐ Other pulmonary syndrome *(excluding pulmonary hemorrhage)* – ***Go to question 5.***

Toxicity

- ☐ Neurotoxicity (ICANS) ***– Go to question 6.***
- ☐ Tumor lysis syndrome – ***Go to question 6***

Vascular

- ☐ Disseminated intravascular coagulation (DIC) ***– Go to question 6.***
- ☐ Thromboembolism ***– Go to question 6.***
- ☐ Thrombotic microangiopathy (TMA) (Thrombotic thrombocytopenic purpura (TTP)/Hemolytic Uremic Syndrome (HUS)) ***– Go to question 6.***
- ☐ Other vascular - ***Go to question 5.***

Other

- ☐ Accidental death ***– Go to question 6.***
- ☐ Suicide ***– Go to question 6.***
- ☐ Other cause - ***Go to question 5.***

5. Specify:____

Copyright © 2021 National Marrow Donor Program and The Medical College of Wisconsin, Inc. All rights reserved.

Contributing Cause of Death

6. Contributing cause of death *(check all that apply)*

- ☐ Recurrence / persistence / progression of disease for which the infusion was performed ***– Go to First Name***
- ☐ Acute GVHD – ***Go to First Name***
- ☐ Chronic GVHD ***– Go to First Name***
- ☐ Graft rejection or failure ***– Go to First Name***
- ☐ Cytokine release syndrome ***– Go to First Name***

Hemorrhage

- ☐ Diffuse alveolar hemorrhage (DAH) ***– Go to First Name***
- ☐ Gastrointestinal hemorrhage ***– Go to First Name***
- ☐ Hemorrhagic cystitis ***– Go to First Name***
- ☐ Intracranial hemorrhage ***– Go to First Name***
- ☐ Pulmonary hemorrhage ***– Go to First Name***
- ☐ Other hemorrhage – ***Go to question 7.***

Infection

- ☐ Bacterial infection ***– Go to First Name***
- ☐ COVID-19 (SARS-CoV-2) ***– Go to First Name***
- ☐ Fungal infection ***– Go to First Name***
- ☐ Infection, organism not identified ***– Go to First Name***
- ☐ Protozoal infection ***– Go to First Name***
- ☐ Viral infection ***– Go to First Name***
- ☐ Other infection – ***Go to question 7.***

Malignancy

- ☐ New malignancy *(post-infusion)* ***– Go to First Name***
- ☐ Prior malignancy *(malignancy initially diagnosed prior to infusion, other than the malignancy for which the infusion was performed)****– Go to First Name***

Organ failure (not due to GVHD or infection)

- ☐ Cardiac failure ***– Go to First Name***
- ☐ Central nervous system (CNS) failure ***– Go to First Name***
- ☐ Gastrointestinal (GI) failure *(not liver)* ***– Go to First Name***
- ☐ Liver failure (not VOD) ***– Go to First Name***
- ☐ Multiple organ failure – ***Go to question 7.***
- ☐ Pulmonary failure***– Go to First Name***

Copyright © 2021 National Marrow Donor Program and The Medical College of Wisconsin, Inc. All rights reserved.

- ☐ Renal failure ***– Go to First Name***
- ☐ Veno-occlusive disease (VOD) / sinusoidal obstruction syndrome (SOS) ***– Go to First Name***
- ☐ Other organ failure – ***Go to question 7.***

Pulmonary

- ☐ Acute respiratory distress syndrome (ARDS) *(other than IPS)* ***– Go to First Name***
- ☐ Diffuse alveolar damage *(without hemorrhage)* ***– Go to First Name***
- ☐ Idiopathic pneumonia syndrome (IPS) ***– Go to First Name***
- ☐ Pneumonitis due to Cytomegalovirus (CMV) ***– Go to First Name***
- ☐ Pneumonitis due to other virus ***– Go to First Name***
- ☐ Other pulmonary syndrome *(excluding pulmonary hemorrhage)* – ***Go to question 7.***

Toxicity

- ☐ Neurotoxicity (ICANS) ***– Go to First Name***
- ☐ Tumor lysis syndrome – ***Go to First Name***

Vascular

- ☐ Disseminated intravascular coagulation (DIC) ***– Go to First Name***
- ☐ Thromboembolism ***– Go to First Name***
- ☐ Thrombotic microangiopathy (TMA) (Thrombotic thrombocytopenic purpura (TTP) / Hemolytic Uremic Syndrome (HUS)) ***– Go to First Name***
- ☐ Other vascular - ***Go to question 7.***

Other

- ☐ Accidental death ***– Go to First Name***
- ☐ Suicide ***– Go to First Name***
- ☐ Other cause - ***Go to question 7.***

7. Specify:____

First Name:____

Last Name: ____

E-mail address: ____

Date: ___ ___ ___ ___ — ___ ___ — ___ ___

YYYY MM DD

Copyright © 2021 National Marrow Donor Program and The Medical College of Wisconsin, Inc. All rights reserved.