ERROR CORRECTION FORM

Sequence Number: | | | | | | | | | | | | | | |

CIBMTR Recipient ID: | | | | | | | | | | |

Visit:
☐ 100 day
☐ 6 month
☐ | | year

Today's Date: Month | | Day | | Year | 2 | 0 | | |

Infusion Date: Month | | Day | | Year | 2 | 0 | | |

CIBMTR Center Number: | | | | | |

Initials: | |

CIBMTR
CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Systemic Sclerosis Post-HSCT Data

Registry Use Only

Sequence Number:

Date Received:

CIBMTR Center Number: | | | | | |

CIBMTR Recipient ID: | | | | | | | | | | |

Today's Date: Month | | Day | | Year | 2 | 0 | | |

Date of HSCT for which this form is being completed: 🕮 Month | | Day | | Year | | | | |

HSCT type: ☐ autologous ☐ allogeneic, unrelated ☐ allogeneic, related ☐ syngeneic (identical twin)

Product type: ☐ marrow ☐ PBSC ☐ cord blood ☐ other product, specify: _____

Visit: ☐ 100 day ☐ 6 month ☐ 1 year ☐ 2 years ☐ > 2 years, specify: | |

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.

Disease Assessment Post-HSCT

1. Specify the date the recipient was evaluated for this report: Month | | Day | | Year | 2 | 0 | | |

Post-HSCT Treatment for Systemic Sclerosis

2. Did the recipient receive any treatment for systemic sclerosis since the date of the last report?
   1 ☐ yes → **Continue with table below**
   2 ☐ no → **Continue with question 59**
   3 ☐ unknown

Therapy Given?	Reason for Therapy Code (see page 2)		Date Therapy Started (Month / Day / Year)	Currently Receiving?
3. Antithymocyte globulin (ATG) / antilymphocyte globulin (ALG) 1 ☐ yes → 4. ☐ 2 ☐ no 3 ☐ unknown	5. If Code 4 — Other reason, specify: _____	6.	2 0	7. 1 ☐ yes 2 ☐ no
8. Cyclophosphamide (CTX, Cytoxan, Neosar) 1 ☐ yes → 9. ☐ 2 ☐ no 3 ☐ unknown	10. If Code 4 — Other reason, specify: _____	11.	2 0	12. 1 ☐ yes 2 ☐ no
13. Cyclosporine (CsA, Neoral, Sandimmune) 1 ☐ yes → 14. ☐ 2 ☐ no 3 ☐ unknown	15. If Code 4 — Other reason, specify: _____	16.	2 0	17. 1 ☐ yes 2 ☐ no
18. D-penicillamine (penicillamine, Cuprimine, Depen) 1 ☐ yes → 19. ☐ 2 ☐ no 3 ☐ unknown	20. If Code 4 — Other reason, specify: _____	21.	2 0	22. 1 ☐ yes 2 ☐ no

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ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ Year 20____

Infusion Date: Month ____ Day ____ Year 20____

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

	Therapy Given?	Reason for Therapy Code (see below)		Date Therapy Started (Month / Day / Year)	Currently Receiving?
23. Methotrexate (MTX, Folex)	1 ☐ yes → 24. ☐ 2 ☐ no 3 ☐ unknown		25. If Code 4 — Other reason, specify:	26. ____ / ____ / 20____	27. 1 ☐ yes 2 ☐ no
28. Mycophenolate mofetil (MMF, CellCept)	1 ☐ yes → 29. ☐ 2 ☐ no 3 ☐ unknown		30. If Code 4 — Other reason, specify:	31. ____ / ____ / 20____	32. 1 ☐ yes 2 ☐ no
33. Phototherapy	1 ☐ yes → 34. ☐ 2 ☐ no 3 ☐ unknown		35. If Code 4 — Other reason, specify:	36. ____ / ____ / 20____	37. 1 ☐ yes 2 ☐ no
38. Prednisone (Intensol, Sterapred) or equivalent	1 ☐ yes → 39. ☐ 2 ☐ no 3 ☐ unknown		40. If Code 4 — Other reason, specify:	41. ____ / ____ / 20____	42. 1 ☐ yes 2 ☐ no
43. Prostanoids / prostaglandin analogs	1 ☐ yes → 44. ☐ 2 ☐ no 3 ☐ unknown		45. If Code 4 — Other reason, specify:	46. ____ / ____ / 20____	47. 1 ☐ yes 2 ☐ no
48. Tacrolimus (FK 506, Prograf)	1 ☐ yes → 49. ☐ 2 ☐ no 3 ☐ unknown		50. If Code 4 — Other reason, specify:	51. ____ / ____ / 20____	52. 1 ☐ yes 2 ☐ no
53. Other treatment	1 ☐ yes → 54. ☐ 2 ☐ no 3 ☐ unknown		55. If Code 4 — Other reason, specify:	56. ____ / ____ / 20____	57. 1 ☐ yes 2 ☐ no

58. Specify other treatment: _____

Reason for Therapy Codes
1 planned per protocol **2** continued from prior to HSCT **3** relapse / progression of SSC **4** other reason **5** reason unknown

Disease Status at the Time of Evaluation for This Reporting Period

59. Date of evaluation for this reporting period: Month ____ Day ____ Year 20____

60. What was the extent of cutaneous systemic sclerosis at the time of evaluation for this report?
1 ☐ limited (cutaneous thickening distal (but not proximal) to elbows or knees)
2 ☐ diffuse
3 ☐ unknown

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ERROR CORRECTION FORM

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CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ 20__ Year

Infusion Date: Month ____ Day ____ 20__ Year

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

Specify skin thickness for the following sites as determined by clinical palpation performed at the time of evaluation for this report:
Clements P, Lachenbruch P, Seibold J, White B, Weiner S, Martin R, et al. Inter and intraobserver variability of total skin thickness score (modified Rodnan TSS) in systemic sclerosis. J Rheumatol 1995; 22:1281-1285.

Anatomic Area	Modified Rodnan Skin Thickness Score (MRSS) normal	mild	moderate	severe *
61. Face	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
62. Anterior chest	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
63. Abdomen	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
64. Upper arm – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
65. Upper arm – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
66. Forearms – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
67. Forearms – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
68. Dorsum of hand – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
69. Dorsum of hand – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
70. Fingers – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
71. Fingers – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
72. Thigh – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
73. Thigh – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
74. Lower leg – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
75. Lower leg – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
76. Dorsum of foot – left	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3
77. Dorsum of foot – right	1 ☐ score 0	2 ☐ score 1	3 ☐ score 2	4 ☐ score 3

* Severe = inability to pinch skin into a fold

78. Total modified Rodnan Skin Score: *(add scores from questions 61–77)* ____

Specify the following clinical findings at the time of evaluation for this report:

79. Changes in skin pigmentation:
1 ☐ present
2 ☐ absent
3 ☐ unknown

80. Raynaud's phenomenon:
1 ☐ present
2 ☐ absent
3 ☐ unknown

81. Painful digital ulcers:
1 ☐ present → 82. Specify number of digital ulcers: ____
2 ☐ absent
3 ☐ unknown

83. Gut dysmotility:
1 ☐ present
2 ☐ absent
3 ☐ unknown

84. Malabsorption:
1 ☐ present
2 ☐ absent
3 ☐ unknown

85. Weight loss > 10% of body weight:
1 ☐ present
2 ☐ absent
3 ☐ unknown

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ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ Year 20____

Infusion Date: Month ____ Day ____ Year 20____

CIBMTR Center Number:

Initials:

CIBMTR Center Number: CIBMTR Recipient ID:

86. Muscle weakness:
1 ☐ present
2 ☐ absent
3 ☐ unknown

87. Joint tenderness:
1 ☐ present → 88. Specify number of joints affected: ____
2 ☐ absent
3 ☐ unknown

89. Tendon friction rubs:
1 ☐ present → 90. Specify number of sites affected: ____
2 ☐ absent
3 ☐ unknown

91. Contractures:
1 ☐ present
2 ☐ absent
3 ☐ unknown

Laboratory Studies at the Time of Evaluation for This Reporting Period

92. Serum creatinine:
1 ☐ known → ____.____
2 ☐ not known
Specify units:
1 ☐ mg/dL
2 ☐ µmol/L
3 ☐ mmol/L

93. Creatinine clearance:
1 ☐ known → ____.____
2 ☐ not known
1 ☐ mL/min
2 ☐ mL/sec

94. Creatinine phosphokinase:
1 ☐ known → ____.____
2 ☐ not known
1 ☐ U/L
2 ☐ µkat/L

95. Blood urea nitrogen:
1 ☐ known → ____.____
2 ☐ not known
1 ☐ mg/dL
2 ☐ mmol/L

96. Was there evidence of hematuria at the time of evaluation for this report?
1 ☐ yes, present
2 ☐ no, absent
3 ☐ unknown

97. Was there evidence of proteinuria at the time of evaluation for this report?
1 ☐ yes, present
2 ☐ no, absent
3 ☐ unknown

98. Thyroid stimulating hormone (TSH):
1 ☐ known → ____.____
2 ☐ not known
1 ☐ mU/L
2 ☐ µU/mL

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Sequence Number:

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Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ 20__ Year

Infusion Date: Month ____ Day ____ 20__ Year

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

99. Was any testing for autoantibodies performed since the date of the last report?
1 ☐ yes → Specify the test results for the following autoantibodies:
2 ☐ no
3 ☐ unknown

100. Anti-centromere: 1 ☐ positive 2 ☐ negative 3 ☐ inconclusive 4 ☐ not tested / unknown
101. Anti-DNA topoisomerase I (Scl-70): 1 ☐ positive 2 ☐ negative 3 ☐ inconclusive 4 ☐ not tested / unknown
102. Anti-nuclear: 1 ☐ positive 2 ☐ negative 3 ☐ inconclusive 4 ☐ not tested / unknown
103. Anti-SS-A: 1 ☐ positive 2 ☐ negative 3 ☐ inconclusive 4 ☐ not tested / unknown
104. Anti-SS-B: 1 ☐ positive 2 ☐ negative 3 ☐ inconclusive 4 ☐ not tested / unknown

Specify the results of the following pulmonary function tests performed since the date of the last report:

105. Was dyspnea present on exertion?
1 ☐ yes
2 ☐ no
3 ☐ unknown

106. Vital capacity (VC):
1 ☐ known → ____.____ % (predicted value) → 107. Was the actual VC value in the normal range (≥ 80% of predicted value)?
2 ☐ not known
1 ☐ yes
2 ☐ no

108. D_LCO:
1 ☐ known → ____.____ % (predicted value) → 109. Was the actual D_LCO value in the normal range (≥ 80% of predicted value)?
2 ☐ not known
1 ☐ yes
2 ☐ no

110. D_LCO corrected for hemoglobin:
1 ☐ known → ____.____ % (predicted value) → 111. Was the D_LCO value (corrected for hemoglobin) in the normal range (≥ 80% of predicted value)?
2 ☐ not known
1 ☐ yes
2 ☐ no

112. Was oxygen desaturation present on exercise testing?
1 ☐ yes
2 ☐ no
3 ☐ unknown

113. Was ground glass appearance present on chest x-ray?
1 ☐ yes
2 ☐ no
3 ☐ unknown

114. Was a high resolution chest CT scan performed?
1 ☐ yes → 115. Was ground glass appearance present on CT scan?
2 ☐ no
3 ☐ unknown
1 ☐ yes
2 ☐ no
3 ☐ unknown

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ERROR CORRECTION FORM

Sequence Number: | | | | | | | | | | | | | | |

CIBMTR Recipient ID: | | | | | | | | | | |

Visit:
☐ 100 day
☐ 6 month
☐ | | year

Today's Date: Month | | Day | | 2 0 | | Year

Infusion Date: Month | | Day | | 2 0 | | Year

CIBMTR Center Number: | | | | | |

Initials: | |

CIBMTR Center Number: | | | | | |

CIBMTR Recipient ID: | | | | | | | | | | |

116. Was pulmonary artery hypertension present?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

117. Specify the mean pulmonary artery pressure (PAP) level:
1 ☐ known → | | mm/Hg
2 ☐ unknown

118. Specify the method used to examine the PAP level:
1 ☐ echocardiogram
2 ☐ catheterization

119. Was systemic hypertension present that required treatment?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

Specify treatment(s) given for hypertension:

120. ACE inhibitor
1 ☐ yes
2 ☐ no

121. Other antihypertensive therapy
1 ☐ yes →
2 ☐ no

122. Specify antihypertensive therapy: _____

123. Specify the duration of antihypertensive therapy: | | | months

124. Was arrythmia present that required treatment?
1 ☐ yes
2 ☐ no
3 ☐ unknown

125. Was an echocardiogram performed at the time of evaluation for this report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

126. Was pericardial effusion present?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

127. Specify the size of the area of accumulated excess fluid:
1 ☐ small
2 ☐ moderate
3 ☐ large

128. Specify the left ventricular ejection fraction:
1 ☐ known → | | %
2 ☐ not known

129. Was a multiple gate acquisition scan (MUGA test / nuclear ventriculography) performed at the time of evaluation for this report?
1 ☐ yes →
2 ☐ no
3 ☐ unknown

130. Specify the left ventricular ejection fraction: | | %

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ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Visit:
☐ 100 day
☐ 6 month
☐ ____ year

Today's Date: Month ____ Day ____ Year 20____

Infusion Date: Month ____ Day ____ Year 20____

CIBMTR Center Number:

Initials:

CIBMTR Center Number:

CIBMTR Recipient ID:

Functional Assessment at the Time of Evaluation for This Report

131. Did the recipient complete a modified Health Assessment Questionnaire (HAQ) for Scleroderma at the time of evaluation for this report?
Steen VD, Medsger Jr. TA. The value of the Health Assessment Questionnaire and special patient-generated scales to demonstrate change in systemic sclerosis patients over time. Arthritis Rheum 1997; 40 (11): 1984–1991.

1 ☐ yes →
2 ☐ no
3 ☐ unknown

132. Recipient's score:

133. Worst possible score:

134. Best possible score:

135. Signed: _____
Person completing form

Please print name: _____

Phone number: (_____) _____

Fax number: (_____) _____

E-mail address: _____

Fax this form to your designated campus (Milwaukee 414-805-0714 or Minneapolis 612-627-5895).