

**INSERT XXIV**  
**Systemic Sclerosis (SSc)**

**FOR REGISTRY USE ONLY:**  
I.D.  -  -   
Date received:

TEAM:  IUBMID:   
*(Institutional Unique Blood or Marrow Transplant Identification Number)*

Registry (circle one): *IBMTR* ABMTR EBMT

Date of transplant for which this form is being completed:     
Month Day Year

Date of report:     
Month Day Year

**Pretransplant Information\***

\* If this is a report of a second (or subsequent) transplant, check here  and go to Q.131

1. Date of diagnosis:     
Month Day Year

2. Extent of cutaneous Systemic Sclerosis at diagnosis:
- 1  Limited (cutaneous thickening distal to elbows or knees, but not proximal)
  - 0  Diffuse
  - 8  Unknown

**Laboratory Data at Diagnosis**

		<u>Specify Units</u>	<u>Unknown</u>
3. Hemoglobin:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> g/dL 2 <input type="checkbox"/> g/L 3 <input type="checkbox"/> mmol/L	<input type="checkbox"/>
4. Hematocrit:	<input type="text"/> <input type="text"/> <input type="text"/> %		<input type="checkbox"/>
5. WBC:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>	1 <input type="checkbox"/> x10 <sup>9</sup> /L (x10 <sup>3</sup> /mm <sup>3</sup> ) 2 <input type="checkbox"/> x10 <sup>6</sup> /L	<input type="checkbox"/>
6. Platelets:	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> x10 <sup>9</sup> /L (x10 <sup>3</sup> /mm <sup>3</sup> ) 2 <input type="checkbox"/> x10 <sup>6</sup> /L	<input type="checkbox"/>
7. Blood urea nitrogen:	<input type="text"/> <input type="text"/> . <input type="text"/>	1 <input type="checkbox"/> mg/dL 2 <input type="checkbox"/> mmol/L	<input type="checkbox"/>
8. Serum creatinine:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> mg/dL 2 <input type="checkbox"/> mmol/L 3 <input type="checkbox"/> μmol/L	<input type="checkbox"/>
9. Hematuria:	1 <input type="checkbox"/> Present 0 <input type="checkbox"/> Absent	<input type="checkbox"/> Unknown	
10. Proteinuria:	1 <input type="checkbox"/> Present 0 <input type="checkbox"/> Absent	<input type="checkbox"/> Unknown	
11. Creatinine clearance:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>	1 <input type="checkbox"/> ml/min 2 <input type="checkbox"/> ml/s	<input type="checkbox"/>
12. Thyroid stimulating hormone (TSH):	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/>	1 <input type="checkbox"/> mU/L or 2 <input type="checkbox"/> μU/ml	<input type="checkbox"/>
13. Creatinine phosphokinase:	<input type="text"/> <input type="text"/> <input type="text"/> . <input type="text"/> <input type="text"/>	1 <input type="checkbox"/> U/L 2 <input type="checkbox"/> μkat/L	<input type="checkbox"/>

Retired - Not for Data Submission

TEAM:

IUBMID:

14. Were tests for autoantibodies done at diagnosis?  Yes  No  Unknown

Specify antibody:		Positive	Negative	Inconclusive	Not tested/ Unknown
15.	Anti-centromere:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Anti-nuclear:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Anti-DNA topoisomerase I (Scl-70):	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Anti-SSA:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Anti-SSB:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Reason for Stopping Codes**  
 1 = Failure  
 2 = Toxicity  
 3 = Still receiving at mobilization  
 7 = Other, specify  
 8 = Unknown

### Therapy History

Cite all disease-modifying treatments received by patient between time of diagnosis and prior to mobilization for stem cell collection (or high-dose therapy if mobilization not done):

Yes	No	Unk	Treatment	Reason for Stopping (use codes above)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	20. ATG/ALG	21. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	22. Cyclophosphamide	22. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	24. Cyclosporine	25. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	26. D-penicillamine	27. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	28. Methotrexate	31. <input type="checkbox"/> —If Other, specify: _____

Specify:

29. Maximum weekly dose:    mg  Unknown

30. Duration of therapy:   months  weeks  Unknown

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	32. Mycophenolate Mofetil	33. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	34. Non-steroidal anti-inflammatory	35. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	36. Phototherapy	37. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	38. Prednisone or equivalent	39. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	40. Prostanoids/Prostaglandin analogs	41. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	42. Tacrolimus/FK506	43. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	44. Other, specify: _____	45. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	46. Other, specify: _____	47. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	48. Other, specify: _____	49. <input type="checkbox"/> —If Other, specify: _____
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	50. Other, specify: _____	51. <input type="checkbox"/> —If Other, specify: _____

TEAM:

IUBMID:

### Evaluation Prior to Mobilization for Stem Cell Collection\*

\* Evaluation should be performed  $\leq 4$  weeks prior to mobilization for stem cell collection; if patient did not receive mobilization therapy, check here  and go to Q.131

52. Date of evaluation prior to mobilization for stem cell collection:        
Month Day Year

53. Extent of cutaneous Systemic Sclerosis just prior to mobilization:
- 1  Limited (cutaneous thickening distal to elbows or knees, but not proximal)
  - 0  Diffuse
  - 8  Unknown

Skin thickness (specify modified Rodnan Skin Score evaluating skin thickness by clinical palpation) prior to mobilization:

Anatomic area	Thickness Score			
	0 (normal)	1 (mild)	2 (moderate)	3 (severe*)
54. Face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. Anterior Chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. Abdomen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fingers				
57. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
58. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Hands				
59. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
60. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Forearms				
61. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
62. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper Arms				
63. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
64. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thighs				
65. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
66. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lower Legs				
67. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
68. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Feet				
69. Rt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
70. Lt.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Severe = inability to pinch skin into a fold

**Reference**  
 (Clements P, et al, J Rheumatol, 1995, 22:1281-5)

71. Total modified Rodnan Skin Score (add scores for Q.54 through Q.70):    Unknown

Retired - Not for Data Submission

TEAM:

IUBMID:

Other clinical findings prior to mobilization:

72. Changes in skin pigmentation 1  Present 0  Absent 8  Unknown

73. Raynaud's phenomenon 1  Present 0  Absent 8  Unknown

74. Painful digital ulcers 1  Present 0  Absent 8  Unknown

75. Specify number:

76. Gut dysmotility 1  Present 0  Absent 8  Unknown

77. Malabsorption 1  Present 0  Absent 8  Unknown

78. Weight loss >10% of body weight 1  Present 0  Absent 8  Unknown

79. Muscle weakness 1  Present 0  Absent 8  Unknown

80. Joint tenderness 1  Present 0  Absent 8  Unknown

81. Specify number of joints:

82. Tendon friction rubs 1  Present 0  Absent 8  Unknown

83. Specify number of sites:

84. Contractures 1  Present 0  Absent 8  Unknown

### Laboratory Values Prior to Mobilization

85. Hemoglobin:        1  g/dL 2  g/L 3  mmol/L  Specify Units Unknown

86. Hematocrit:   %

87. WBC:        1  x10<sup>9</sup>/L (x10<sup>3</sup>/mm<sup>3</sup>) 2  x10<sup>6</sup>/L

88. Platelets:        1  x10<sup>9</sup>/L (x10<sup>3</sup>/mm<sup>3</sup>) 2  x10<sup>6</sup>/L

89. Blood urea nitrogen:     1  mg/dL 2  mmol/L

90. Serum creatinine:       1  mg/dL 2  mmol/L 3  μmol/L

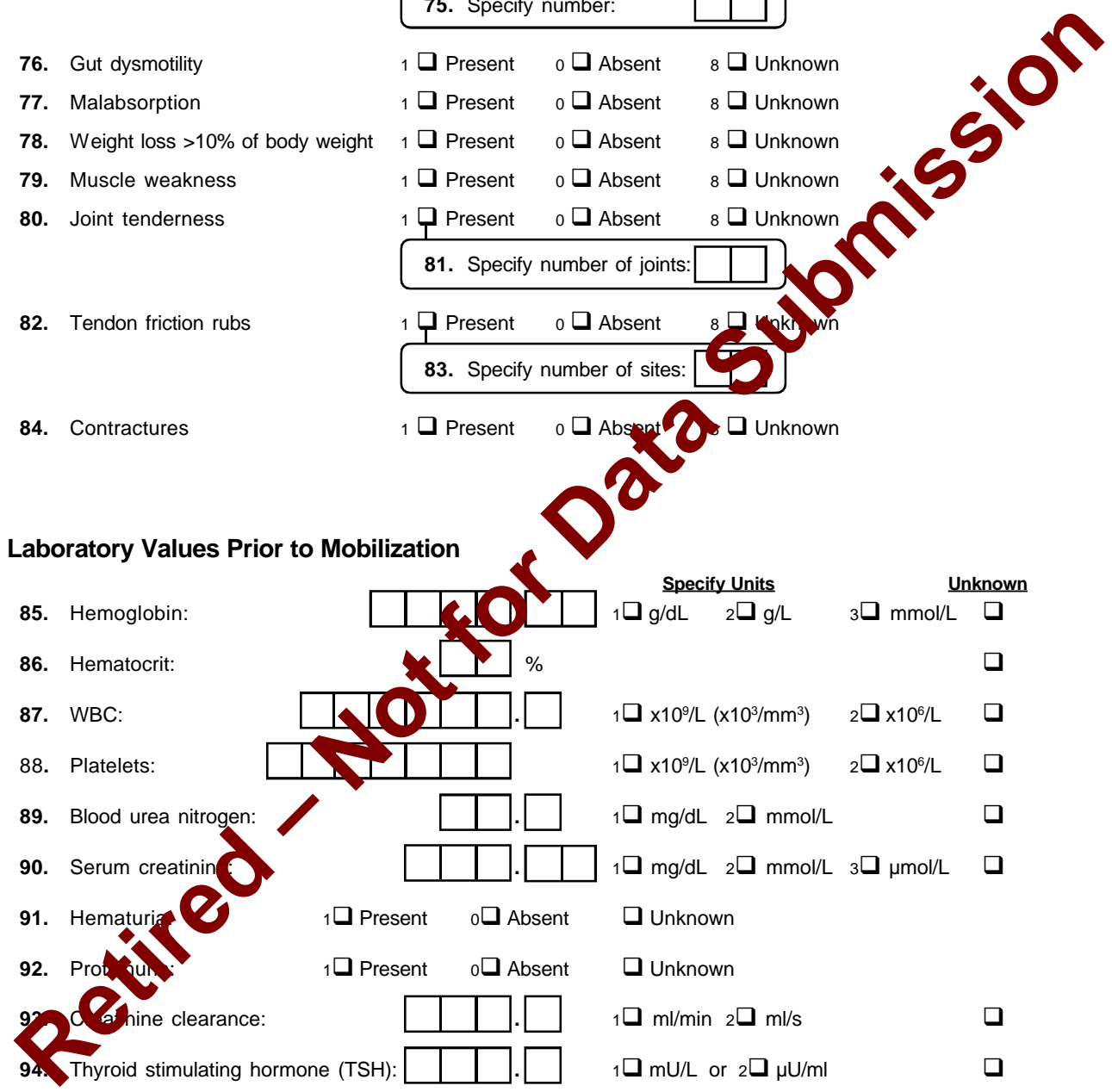
91. Hematuria: 1  Present 0  Absent  Unknown

92. Proteinuria: 1  Present 0  Absent  Unknown

93. Creatinine clearance:       1  ml/min 2  ml/s

94. Thyroid stimulating hormone (TSH):      1  mU/L or 2  μU/ml

95. Creatinine phosphokinase:       1  U/L 2  μkat/L



TEAM:

IUBMID:

96. Were tests for autoantibodies done? 1  Yes 0  No 8  Unknown

Specify antibody:	Positive	Negative	Inconclusive	Not tested/ Unknown
97. Anti-centromere:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
98. Anti-nuclear:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
99. Anti-DNA topoisomerase I (Scl-70):	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
100. Anti-SSA:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
101. Anti-SSB:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>

102. Dyspnea on exertion: Yes No Unknown  
1  0  8

Pulmonary function tests:

103. Vital capacity (VC): 1  0  8

<input type="text"/>	<input type="text"/>	<input type="text"/>	% predicted
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104. D<sub>L</sub>CO: 1  0  8

<input type="text"/>	<input type="text"/>	<input type="text"/>	% predicted
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105. D<sub>L</sub>CO: 1  0  8

<input type="text"/>	<input type="text"/>	<input type="text"/>	% corrected for hemoglobin
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106. Oxygen desaturation present on exercise testing: 1  0  8

107. Ground glass appearance on CXR: 1  0  8

108. High resolution chest CT scan done: 1  0  8

109. Was ground glass appearance on CT scan present?  
1  Yes 0  No 8  Unknown

110. Bronchoalveolar lavage (BAL) done: 1  0  8

111. Was alveolitis present? 1  Yes 0  No

113. Pulmonary artery hypertension: 1  0  8

112. Highest % neutrophils in segments tested:

114. Mean PAP:   mm/Hg 8  Unknown

116. Systemic hypertension requiring treatment: 1  0  8

115. Method: 1  Echocardiogram 2  Catheterization

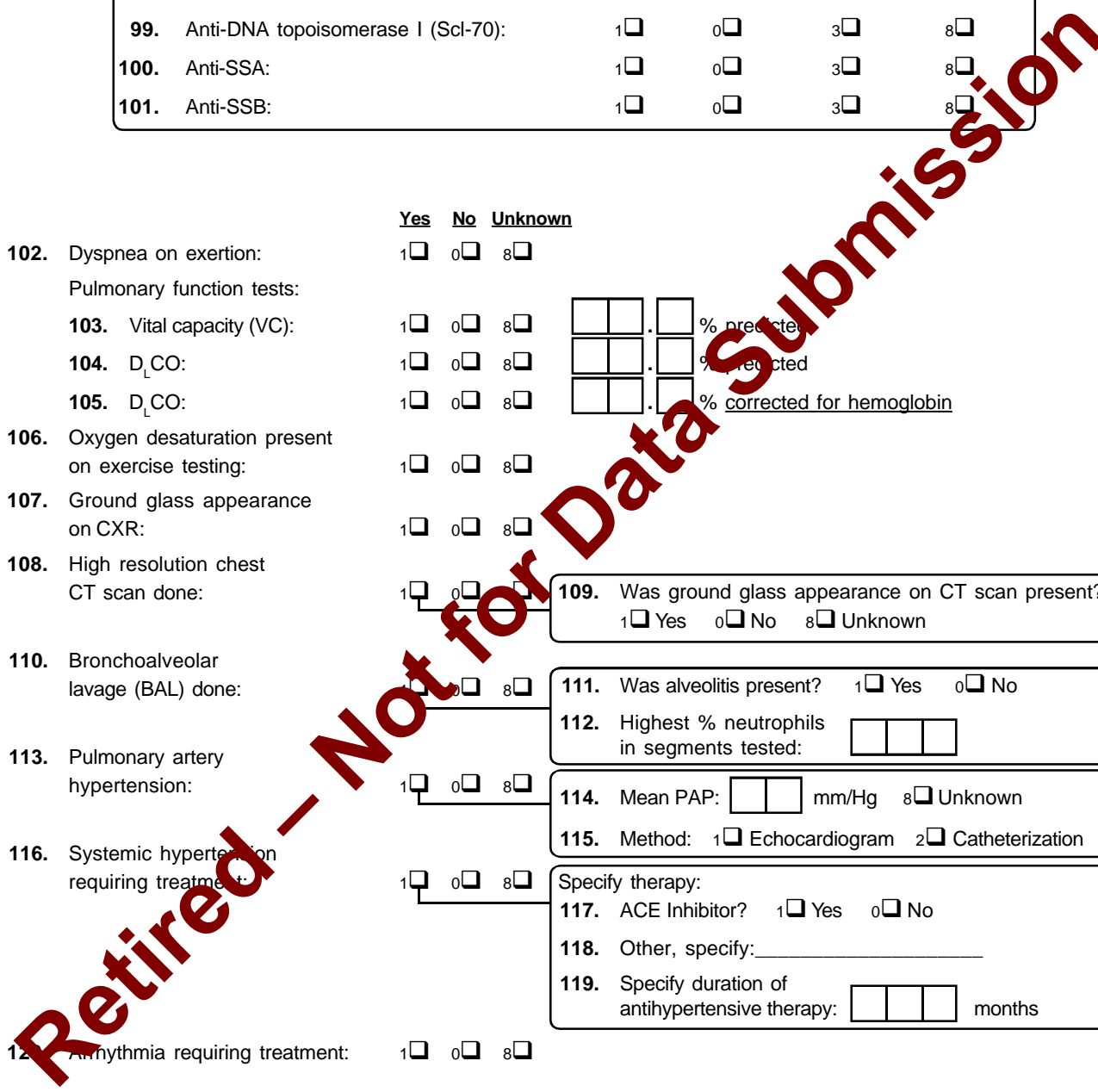
Specify therapy:

117. ACE Inhibitor? 1  Yes 0  No

118. Other, specify: \_\_\_\_\_

119. Specify duration of antihypertensive therapy:    months

120. Arrhythmia requiring treatment: 1  0  8



TEAM:

IUBMID:

**Yes No Unknown**

102. Was an echocardiogram done prior to mobilization?

- 1  Yes
- 0  No

122. Was a pericardial effusion present?  
1  Yes  
0  No

123. Specify: 1  Small 2  Moderate 3  Large

124. Specify left ventricular ejection fraction:   %

125. Was a MUGA done?

- 1  Yes
- 0  No

126. Specify left ventricular ejection fraction:   %

127. Did the patient complete a modified Health Assessment Questionnaire (HAQ) for Scleroderma patients prior to mobilization?

- 1  Yes
- 0  No
- 8  Unknown

Specify:

128. Patient's score:

129. Worst possible score:

130. Best possible score:

**Reference**  
(Steen VD, *Arthritis Rheum*, 1997,  
Nov;40(11):1984-91)

**Retired – Not for Data Submission**

TEAM:

IUBMID:

**Evaluation Prior to Conditioning (High-dose Therapy)\***

*\* Evaluation should be performed  $\leq 2$  weeks prior to conditioning*

131. Was an assessment performed after mobilization and prior to starting conditioning (high-dose therapy)?

1  Yes

0  No Go to Q.206

8  Unknown

132. Date of evaluation prior to conditioning:        
Month Day Year

133. Extent of cutaneous Systemic Sclerosis prior to conditioning:

1  Limited (cutaneous thickening distal to elbows or knees, but not proximal)

0  Diffuse

8  Unknown

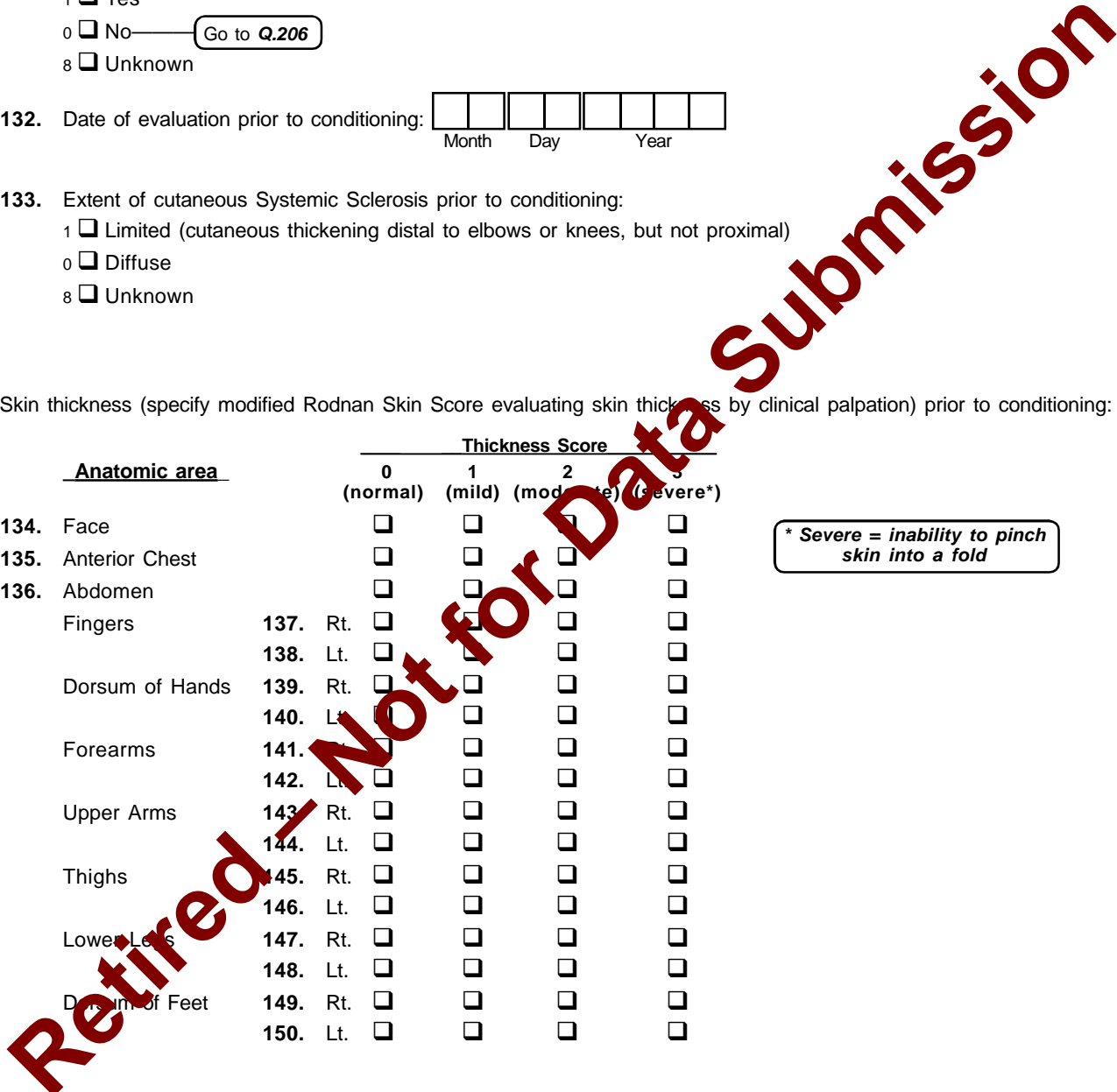
Skin thickness (specify modified Rodnan Skin Score evaluating skin thickness by clinical palpation) prior to conditioning:

Anatomic area	Thickness Score			
	0 (normal)	1 (mild)	2 (moderate)	3 (severe*)
134. Face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
135. Anterior Chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
136. Abdomen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fingers	137. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	138. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Hands	139. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	140. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Forearms	141. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	142. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper Arms	143. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	144. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thighs	145. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	146. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lower Legs	147. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	148. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Feet	149. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	150. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Severe = inability to pinch skin into a fold

151. Total modified Rodnan Skin Score (add scores for Q.134 through Q.150):

Unknown



TEAM: [ ][ ][ ][ ]

IUBMID: [ ][ ][ ][ ][ ][ ][ ]

Other clinical findings prior to conditioning:

152. Changes in skin pigmentation 1  Present 0  Absent 8  Unknown

153. Raynaud's phenomenon 1  Present 0  Absent 8  Unknown

154. Painful digital ulcers 1  Present 0  Absent 8  Unknown

155. Specify number: [ ][ ]

156. Gut dysmotility 1  Present 0  Absent 8  Unknown

157. Malabsorption 1  Present 0  Absent 8  Unknown

158. Weight loss >10% of body weight 1  Present 0  Absent 8  Unknown

159. Muscle weakness 1  Present 0  Absent 8  Unknown

160. Joint tenderness 1  Present 0  Absent 8  Unknown

161. Specify number of joints: [ ][ ]

162. Tendon friction rubs 1  Present 0  Absent 8  Unknown

163. Specify number of sites: [ ][ ]

164. Contractures 1  Present 0  Absent 8  Unknown

Laboratory Values Prior to Conditioning

165. Blood urea nitrogen: [ ][ ][ ] [ ][ ] Specify Units 1  mg/dL 2  mmol/L Unknown

166. Hematuria: 1  Present 0  Absent  Unknown

167. Proteinuria: 1  Present 0  Absent  Unknown

167. Creatinine clearance: [ ][ ][ ][ ] [ ][ ] 1  ml/min 2  ml/s

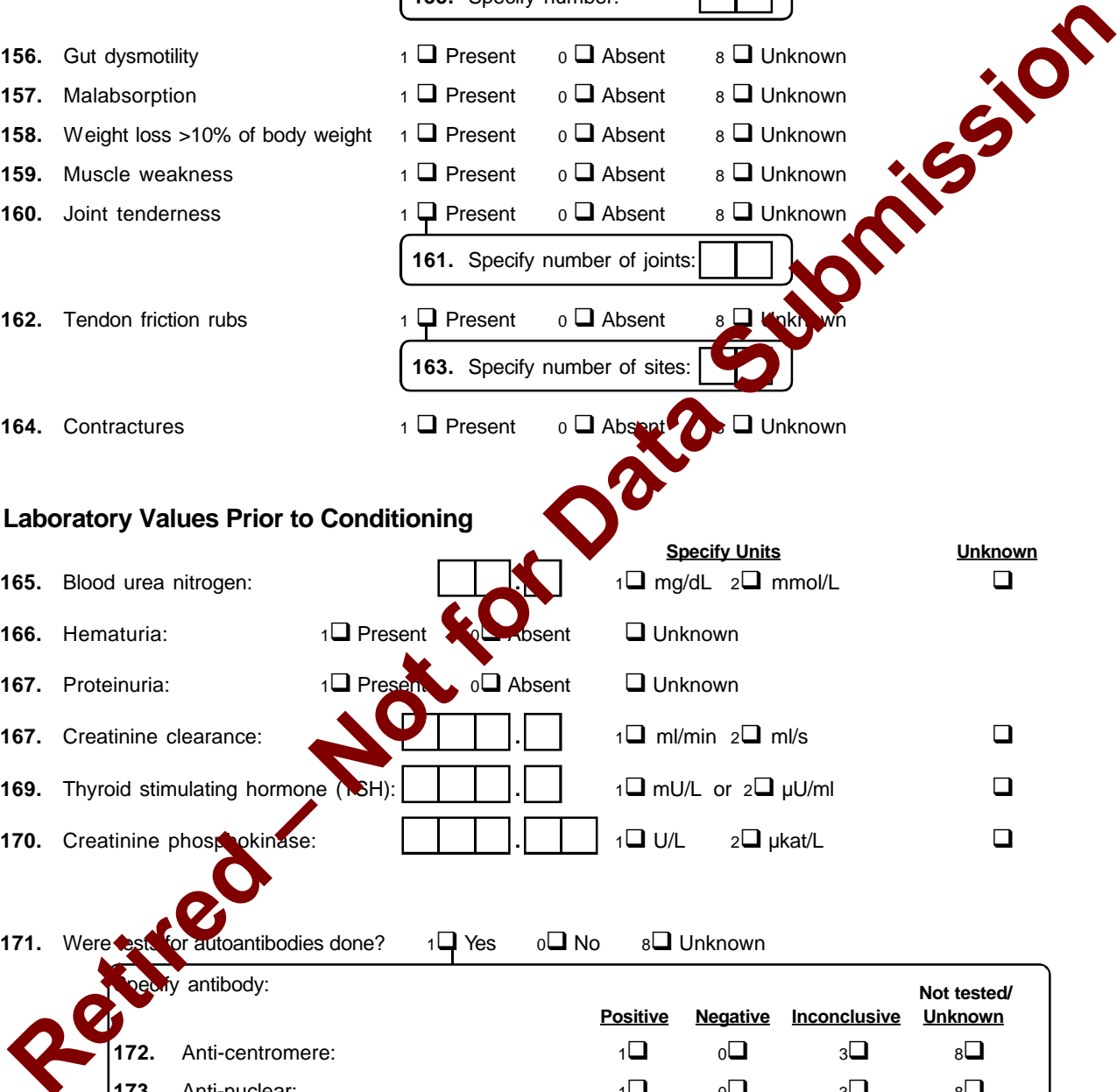
169. Thyroid stimulating hormone (TSH): [ ][ ][ ][ ] [ ][ ] 1  mU/L or 2  μU/ml

170. Creatinine phosphokinase: [ ][ ][ ][ ][ ] [ ][ ] 1  U/L 2  μkat/L

171. Were tests for autoantibodies done? 1  Yes 0  No 8  Unknown

Specify antibody:

	<u>Positive</u>	<u>Negative</u>	<u>Inconclusive</u>	<u>Not tested/ Unknown</u>
172. Anti-centromere:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
173. Anti-nuclear:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
174. Anti-DNA topoisomerase I (Scl-70):	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
175. Anti-SSA:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
176. Anti-SSB:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>





TEAM:

IUBMID:

**Yes No Unknown**

177. Dyspnea on exertion: 1  0  8

Pulmonary function tests:

178. Vital capacity (VC): 1  0  8    .  % predicted

179. D<sub>L</sub>CO: 1  0  8    .  % predicted

180. D<sub>L</sub>CO: 1  0  8    .  % corrected for hemoglobin

181. Oxygen desaturation present on exercise testing: 1  0  8

182. Ground glass appearance on CXR: 1  0  8

183. High resolution chest CT scan done: 1  0  8

184. Was ground glass appearance on CT scan present?  
1  Yes 0  No 8  Unknown

185. Bronchoalveolar lavage (BAL) done: 1  0  8

186. Was alveolitis present? 1  Yes 0  No

187. Highest % neutrophils in segments tested:

188. Pulmonary artery hypertension: 1  0  8

189. Mean PAP:   mm/Hg 8  Unknown

190. Method: 1  Echocardiogram 2  Catheterization

191. Systemic hypertension requiring treatment: 1  0  8

Specify therapy:

1  ACE Inhibitor? 1  Yes 0  No

193. Other, specify: \_\_\_\_\_

194. Specify duration of antihypertensive therapy:    months

195. Arrhythmia requiring treatment: 1  0  8

196. Was an echocardiogram done prior to conditioning?

1  Yes  
0  No

197. Was pericardial effusion present?

1  Yes  
0  No

198. Specify: 1  Small 2  Moderate 3  Large

199. Specify left ventricular ejection fraction:   %

200. Was a MUGA done prior to conditioning?

1  Yes  
0  No

201. Specify left ventricular ejection fraction:   %

202. Did the patient complete a modified Health Assessment Questionnaire (HAQ) for Scleroderma patients prior to conditioning?

1  Yes  
0  No  
8  Unknown

Specify:

203. Patient's score:

204. Worst possible score:

205. Best possible score:

<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>

TEAM:

IUBMID:

The primary reason for transplant included disease involving *(check all that apply)*:

**Yes No Unknown**

- 206. 1  0  8  Lungs
- 207. 1  0  8  Heart
- 208. 1  0  8  GI tract
- 209. 1  0  8  Skin
- 210. 1  0  8  Severe functional impairment
- 211. 1  0  8  Other, specify: \_\_\_\_\_

**Retired – Not for Data Submission**

TEAM:

IUBMID:

### Posttransplant Evaluation\*

*\*To be completed 100 days posttransplant, or at time of death if death occurred <100 days posttransplant, or immediately prior to start of high-dose therapy (conditioning) for second transplant if second transplant done <100 days after first transplant.*

212. Did patient receive treatment for Systemic Sclerosis posttransplant? 1  Yes 0  No 8  Unknown

Cite regimens:		Reason for Therapy				Still Receiving
Yes	No	Unknown	(use codes below)			
213.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	ATG/ALG		1 <input type="checkbox"/>
215.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Cyclophosphamide		1 <input type="checkbox"/>
217.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Cyclosporine		1 <input type="checkbox"/>
219.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	D-penicillamine		1 <input type="checkbox"/>
221.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Methotrexate		1 <input type="checkbox"/>
223.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Mycophenolate Mofetil		1 <input type="checkbox"/>
225.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Phototherapy		1 <input type="checkbox"/>
227.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Prednisone or equivalent		1 <input type="checkbox"/>
228.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Prostanoids/Prostaglandin analogs		1 <input type="checkbox"/>
231.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Tacrolimus/FK506		1 <input type="checkbox"/>
				Other(s), specify:		
233.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>			1 <input type="checkbox"/>
235.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>			1 <input type="checkbox"/>
237.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>			1 <input type="checkbox"/>
239.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>			1 <input type="checkbox"/>

**Reason for Therapy Codes**

- 1 = Planned per protocol
- 2 = Continued from pretransplant
- 3 = Relapse/Progression of systemic sclerosis
- 7 = Other, specify
- 8 = Unknown

Retired - Not for Data Submission

TEAM:

IUBMID:

239. Extent of cutaneous Systemic Sclerosis at current evaluation:
- 1  Limited (cutaneous thickening distal to elbows or knees, but not proximal)
  - 0  Diffuse
  - 8  Unknown

Skin thickness (specify modified Rodnan Skin Score evaluating skin thickness by clinical palpation) at current evaluation.

<u>Anatomic area</u>	<u>Thickness Score</u>			
	0 (normal)	1 (mild)	2 (moderate)	3 (severe*)
240. Face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
241. Anterior Chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
242. Abdomen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fingers	243. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	244. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Hands	245. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	246. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Forearms	247. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	248. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper Arms	249. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	250. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thighs	251. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	252. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lower Legs	253. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	254. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Feet	255. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	256. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\* Severe = inability to pinch skin in a fold

257. Total modified Rodnan Skin Score (add scores for Q.240 through Q.256):

Unknown

Retired - Not for Data Submission

TEAM:

IUBMID:

Other clinical findings at current evaluation:

258. Changes in skin pigmentation 1  Present 0  Absent 8  Unknown

259. Raynaud's phenomenon 1  Present 0  Absent 8  Unknown

260. Painful digital ulcers 1  Present 0  Absent 8  Unknown

261. Specify number:

262. Gut dysmotility 1  Present 0  Absent 8  Unknown

263. Malabsorption 1  Present 0  Absent 8  Unknown

264. Weight loss >10% of body weight 1  Present 0  Absent 8  Unknown

265. Muscle weakness 1  Present 0  Absent 8  Unknown

266. Joint tenderness 1  Present 0  Absent 8  Unknown

267. Specify number of joints:

268. Tendon friction rubs 1  Present 0  Absent 8  Unknown

269. Specify number of sites:

270. Contractures 1  Present 0  Absent 8  Unknown

**Laboratory Data**

271. Blood urea nitrogen:       Specify Units 1  mg/dL 2  mmol/L Unknown

272. Serum creatinine:             Specify Units 1  mg/dL 2  mmol/L 3   $\mu$ mol/L Unknown

273. Hematuria: 1  Present 0  Absent  Unknown

274. Proteinuria: 1  Present 0  Absent  Unknown

275. Creatinine clearance:           Specify Units 1  ml/min 2  ml/s Unknown

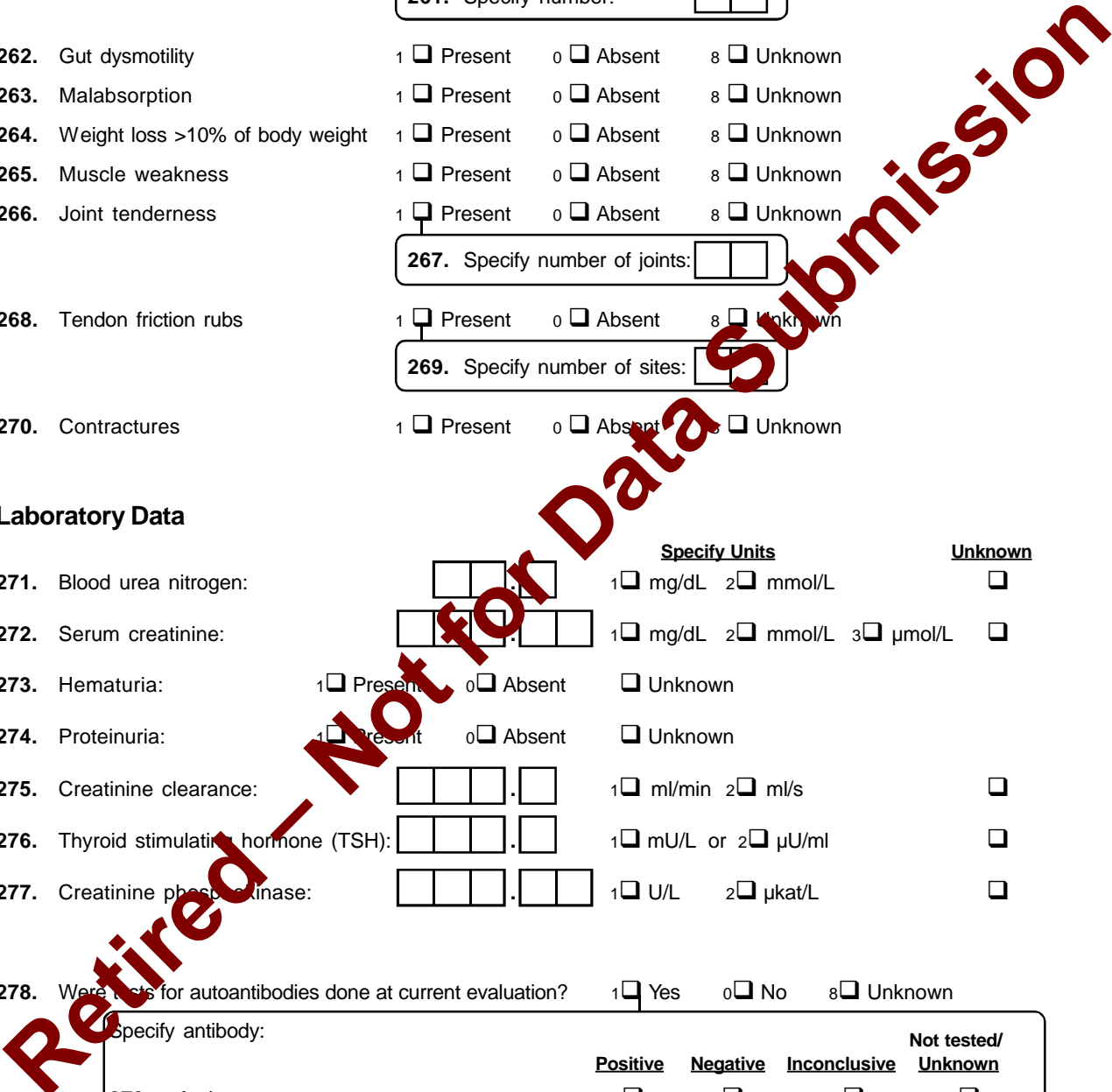
276. Thyroid stimulating hormone (TSH):           Specify Units 1  mU/L or 2   $\mu$ U/ml Unknown

277. Creatinine phosphokinase:           Specify Units 1  U/L 2   $\mu$ kat/L Unknown

278. Were tests for autoantibodies done at current evaluation? 1  Yes 0  No 8  Unknown

Specify antibody:

	<u>Positive</u>	<u>Negative</u>	<u>Inconclusive</u>	<u>Not tested/ Unknown</u>
279. Anti-centromere:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
280. Anti-nuclear:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
281. Anti-DNA topoisomerase I (Scl-70):	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
282. Anti-SSA:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
283. Anti-SSB:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>



TEAM:

IUBMID:

**Yes No Unknown**

284. Dyspnea on exertion: 1  0  8

Pulmonary function tests:

285. Vital capacity (VC): 1  0  8

.  % predicted

286. D<sub>L</sub>CO: 1  0  8

.  % predicted

287. D<sub>L</sub>CO: 1  0  8

.  % corrected for hemoglobin

288. Oxygen desaturation present on exercise testing: 1  0  8

289. Ground glass appearance on CXR: 1  0  8

290. High resolution chest CT scan done: 1  0  8

291. Was ground glass appearance on CT scan present?  
1  Yes 0  No 8  Unknown

292. Pulmonary artery hypertension: 1  0  8

293. Mean PAP:  mm/Hg  Unknown  
294. Method:  Echocardiogram 2  Catheterization

295. Systemic hypertension requiring treatment: 1  0  8

Specify therapy:  
296. ACE inhibitor? 1  Yes 0  No  
297. Other, specify: \_\_\_\_\_  
298. Specify duration of antihypertensive therapy:    months

299. Arrhythmia requiring treatment: 1  0  8

300. Was an echocardiogram done at current evaluation?

1  Yes  
0  No

301. Was a pericardial effusion present?  
1  Yes 0  No  
302. Specify: 1  Small 2  Moderate 3  Large  
303. Specify left ventricular ejection fraction:   %

304. Was a MUGA done at current evaluation?

1  Yes  
0  No

305. Specify left ventricular ejection fraction:   %

306. Did the patient complete a modified Health Assessment Questionnaire (HAQ) for Scleroderma patients at current evaluation?

1  Yes  
0  No  
8  Unknown

Specify:  
307. Patient's score:     
308. Worst possible score:     
309. Best possible score:

