

FOLLOW-UP 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

Follow-up Information*

** Report data for date of last contact or immediately prior to death*

1. Date of evaluation for this report:
Month Day Year

Retired – Not for Data Submission

TEAM:

IUBMID:

29. 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:

Anatomic area	Thickness Score			
	0 (normal)	1 (mild)	2 (moderate)	3 (severe*)
30. Face	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. Anterior Chest	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32. Abdomen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fingers	33. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	34. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Hands	35. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	36. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Forearms	37. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	38. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Upper Arms	39. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	40. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Thighs	41. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	42. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lower Legs	43. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	44. Lt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dorsum of Feet	45. Rt. <input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	46. 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

47. Total modified Rodnan Skin Score (add scores for Q.30 through Q.46):

Unknown

Retired - Not for Data Submission

TEAM:

IUBMID:

Other clinical findings at current evaluation:

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

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

50. Painful digital ulcers 1 Present 0 Absent 8 Unknown

51. Specify number:

52. Gut dysmotility 1 Present 0 Absent 8 Unknown

53. Malabsorption 1 Present 0 Absent 8 Unknown

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

55. Muscle weakness 1 Present 0 Absent 8 Unknown

56. Joint tenderness 1 Present 0 Absent 8 Unknown

57. Specify number of joints:

58. Tendon friction rubs 1 Present 0 Absent 8 Unknown

59. Specify number of sites:

60. Contractures 1 Present 0 Absent 8 Unknown

Laboratory Data

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

62. Serum creatinine: Specify Units 1 mg/dL 2 mmol/L 3 μ mol/L Unknown

63. Hematuria: 1 Present 0 Absent Unknown

64. Proteinuria: 1 Present 0 Absent Unknown

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

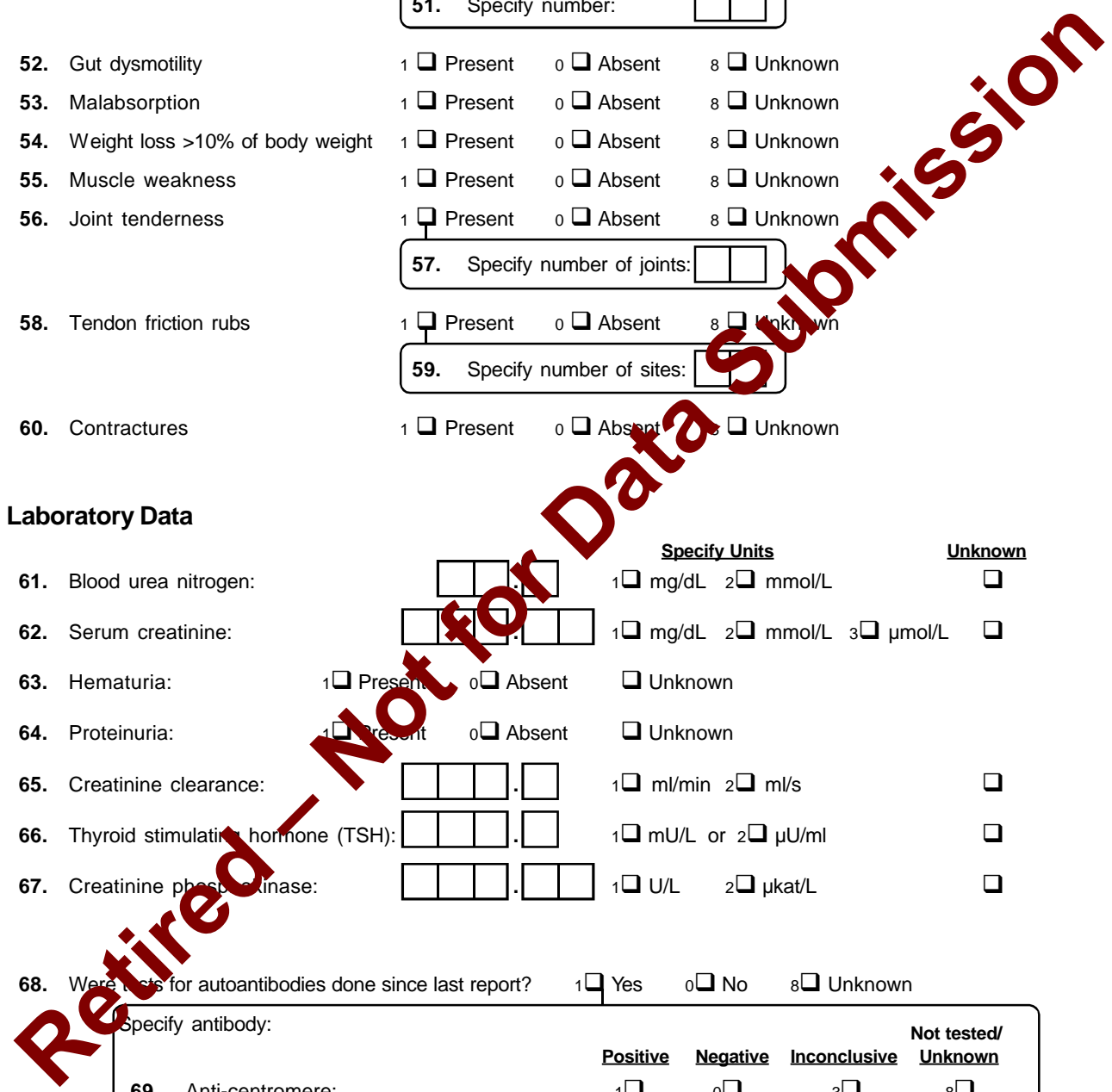
66. Thyroid stimulating hormone (TSH): Specify Units 1 mU/L or 2 μ U/ml Unknown

67. Creatinine phosphokinase: Specify Units 1 U/L 2 μ kat/L Unknown

68. Were tests for autoantibodies done since last report? 1 Yes 0 No 8 Unknown

Specify antibody:

	<u>Positive</u>	<u>Negative</u>	<u>Inconclusive</u>	<u>Not tested/ Unknown</u>
69. Anti-centromere:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
70. Anti-nuclear:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
71. Anti-DNA topoisomerase I (Scl-70):	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
72. Anti-SSA:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>
73. Anti-SSB:	1 <input type="checkbox"/>	0 <input type="checkbox"/>	3 <input type="checkbox"/>	8 <input type="checkbox"/>



TEAM:

IUBMID:

Yes No Unknown

74. Dyspnea on exertion: 1 0 8

Pulmonary function tests:

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

76. D_LCO: 1 0 8 . % predicted

77. D_LCO: 1 0 8 . % corrected for hemoglobin

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

79. Ground glass appearance on CXR: 1 0 8

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

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

82. Pulmonary artery hypertension: 1 0 8

83. Mean PAP: mm/Hg Unknown
84. Method: Echocardiogram 2 Catheterization

85. Systemic hypertension requiring treatment: 1 0 8

Specify therapy:
86. ACE inhibitor? 1 Yes 0 No
87. Other, specify: _____
88. Specify duration of antihypertensive therapy: months

89. Arrhythmia requiring treatment: 1 0 8

90. Was an echocardiogram done at current evaluation?

1 Yes
0 No

91. Was a pericardial effusion present?
1 Yes 0 No
92. Specify: 1 Small 2 Moderate 3 Large
93. Specify left ventricular ejection fraction: %

94. Was a MUGA done at current evaluation?

1 Yes
0 No

95. Specify left ventricular ejection fraction: %

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

1 Yes
0 No
8 Unknown

Specify:
97. Patient's score:
98. Worst possible score:
99. Best possible score:

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

