

**FOLLOW-UP INSERT XXIII**  
**Systemic Lupus Erythematosus (SLE)**

**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:

2. Did patient receive treatment for SLE since last report?

- 1  Yes
- 0  No
- 8  Unknown

**Reason for Therapy Codes**

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

Cite regimens:		<u>Reason for Therapy</u> (use codes above)			Start Date	Still Receiving		
Yes	No	Unk		Month	Day	Year		
3.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Androgens	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
4.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
5.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Anti-malarials	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
6.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
7.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Azathioprine	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
8.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Corticosteroids	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
10.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
11.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Cyclophosphamide	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
12.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
13.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Cyclosporine	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
14.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
15.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Intravenous immune globulin (IVIG)	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
16.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
17.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Lymphocytopenesis	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
18.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
19.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Mycophenolate	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
20.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
21.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	Plasmapheresis	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
22.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
Other(s), specify:								
23.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	_____	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
24.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
25.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	_____	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
26.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
27.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	_____	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
28.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
29.	1 <input type="checkbox"/>	0 <input type="checkbox"/>	8 <input type="checkbox"/>	_____	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>
30.	<input type="checkbox"/>			—If Other, specify:	<input type="text"/>	<input type="text"/>	<input type="text"/>	1 <input type="checkbox"/>

Retired - Not for Data Submission

TEAM:

IUBMID:

**SLEDAI score at current follow-up**

	Yes	No	Unk	Score	Criterion	Definition
31.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Seizures	Recent onset (last 10 days). Exclude metabolic, infectious or drug cause, or seizure due to past irreversible CNS damage.
32.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Psychosis	Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, impoverished thought content, marked illogical thinking, bizarre, disorganized or catatonic behavior. Exclude uremia and drug causes.
33.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Organic brain syndrome	Altered mental function with impaired orientation, memory or other intellectual function, with rapid onset and fluctuating clinical features. Include clouding of consciousness with reduced capacity to focus and inability to sustain attention to environment, plus at least 2 of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness or increased or decreased psychomotor activity. Exclude metabolic, infectious or drug causes.
34.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Visual disturbance	Retinal and eye changes of SLE. Include: cyloid bodies, retinal hemorrhages, serous exudate or hemorrhages in the choroid, optic neuritis, scleritis or episcleritis. Exclude myopia, infection or drug causes.
35.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Cranial nerve disorder	New onset of sensory or motor neuropathy involving cranial nerves. Include vertigo due to lupus.
36.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Lupus headache	Severe, persistent headache may be migrainous, but must be nonresponsive to narcotic analgesia.
37.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	CVA	New onset of cerebrovascular accident(s). Exclude arteriosclerosis or hypertensive causes.
38.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="8"/>	Vasculitis	Ulceration, gangrene, tender finger nodules, periungual infarction, splinter hemorrhages or biopsy or angiogram proof of vasculitis.
39.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="4"/>	Arthritis	More than 2 joints with pain and signs of inflammation (i.e., tenderness, swelling or effusion).
40.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="4"/>	Myositis	Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.
41.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="4"/>	Urinary casts	Heme-granular or red blood cell casts.
42.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="4"/>	Hematuria	>5 red blood cells/high power field. Exclude stone, infection or other cause.
43.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="4"/>	Proteinuria	>0.5 gm/24 hours. New onset or recent increase of >0.5 gm/24 hours.
44.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="4"/>	Pyuria	>5 white blood cells/high power field. Exclude infection.
45.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	New rash	Ongoing inflammatory lupus rash.
46.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	Alopecia	Ongoing abnormal, patchy or diffuse loss of hair due to active lupus.
47.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	Mucosal ulcers	Ongoing oral or nasal ulcerations due to active lupus.
48.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	Pleurisy	Classic and severe pleuritic chest pain or pleural rub or effusion or new pleural thickening due to lupus.
49.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	Pericarditis	Classic and severe pericardial pain or rub or effusion or electrocardiogram confirmation.
50.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	Low complement	Decrease in CH50, C3 or C4 below the lower limit of normal for testing laboratory.
51.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="2"/>	Increased DNA binding	>25% binding by Farr assay or above normal range for testing laboratory.
52.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="1"/>	Fever	>38°C. Exclude infectious cause.
53.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="1"/>	Thrombocytopenia	<100,000 platelets/mm <sup>3</sup> (x 10 <sup>9</sup> /L).
54.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="text" value="1"/>	Leukopenia	<3,000 white blood cells/mm <sup>3</sup> (x 10 <sup>9</sup> /L). Exclude drug causes.

= Total SLEDAI Score

TEAM:

IUBMID:

55. Date of most recent MRI scan of brain since last report:

Month Day Year

Date unknown

MRI not done posttransplant

Go to Q.57

56. MRI scan was:  Normal  Abnormal  Unknown

**Disease Status at Current Evaluation (095-CORE pg 1 Date of last contact)**

- Specify Units** **Unknown**
- 57. Cerebral spinal fluid (CSF) protein        mg/dL  g/L
  - 58. CSF IgG        mg/dL  g/L
  - 59. CSF cell count
  - 60. Creatinine clearance:        mL/min  mL/min
  - 61. 24-hour urine protein:        mg/24hr  mg/24hr
  - 62. Urine RBC/RBC casts?  Yes  No
  - 63. Erythrocyte sedimentation rate:    mm/hr
  - 64. CH50 Reduced?  Yes  No
  - 65. C3 Reduced?  Yes  No
  - 66. C4 Reduced?  Yes  No
  - 67. anti-dsDNA?  Elevated  Normal
  - 68. anti-Sm?  Elevated  Normal
  - 69. anti-SSA (anti-Ro)?  Elevated  Normal
  - 70. anti-SSB (anti-La)?  Elevated  Normal
  - 71. anti-cardiolipin IgG elevated?  Elevated  Normal
  - 72. anti-cardiolipin IgM elevated?  Elevated  Normal
  - 73. lupus-anticoagulant?  Elevated  Normal
  - 74. antinuclear antibody (ANA) test:  Positive  Negative

Date of Assessment: (Month Day Year)

**Pulmonary Function Tests:**

- 76. Vital capacity (VC)       % predicted  Yes  No
- 77. DLCO:       % predicted  Yes  No
- 78. DLCO:       % corrected for hemoglobin  Yes  No
- 79. Oxygen saturation present on exercise testing:  Yes  No

80. Was an echocardiogram done since last report?

Yes  No

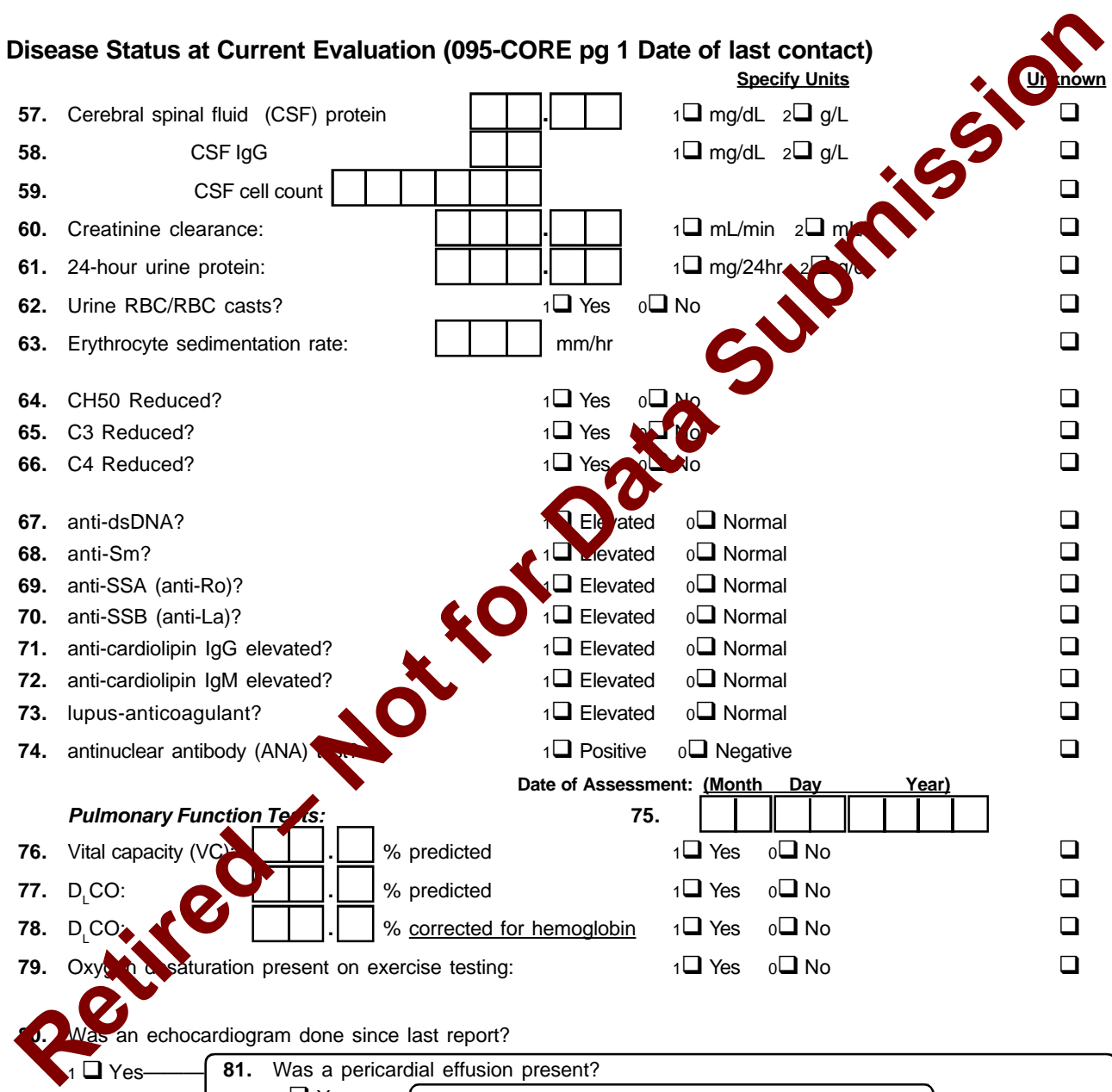
81. Was a pericardial effusion present?

Yes  No **82. Specify:**  Small  Moderate  Large

83. Specify left ventricular ejection fraction:   %  Unknown

84. Was Pulmonary Artery Hypertension present?

Yes  No  Unknown **85. Specify estimated Systolic Pulmonary Artery Pressure:**



TEAM:

IUBMID:

86. Was a MUGA done since last report?

- 1  Yes
- 0  No

87. Specify left ventricular ejection fraction:   %  Unknown

88. Did the patient complete an SF-36™ Health Survey since last report?

- 1  Yes
- 0  No
- 8  Unknown

89. Score reported as:  
1  Transformed Score (range 0-100)  
2  Raw Score  
8  Unknown

90. Physical Functioning:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
91. Role Functioning-Physical:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
92. Role Functioning-Emotional:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
93. Social Functioning:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
94. Bodily Pain:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
95. Mental Health:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
96. Vitality:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown
97. General Health:	<input type="text"/>	<input type="text"/>	<input type="text"/>	.	<input type="text"/>	<input type="checkbox"/> Unknown

98. Did the patient complete a Health Assessment Questionnaire (HAQ) since last report?

- 1  Yes
- 0  No
- 8  Unknown

99. Patient's score:    .

100. Worst possible score:    .

101. Best possible score:    .

Retired – Not for Data Submission