### APPENDIX 1. SLEDAI-2K DATA COLLECTION SHEET

(Check weight in SLEDAI-2K score column if descriptor is present at the time of the visit or in the preceding 10 days.)

| Weight (check) | Descriptor                  | Definition                                                                                                                                                                                                 |
|---------------|-----------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 8             | Seizure                     | Recent onset, exclude metabolic, infectious, or drug causes.                                                                                                                                               |
| 8             | Psychosis                   | Altered ability to function in normal activity due to severe disturbance in the perception of reality. Include hallucinations, incoherence, marked loose associations, improverished thought content, marked illogical thinking, bizarre, disorganized, or catatonic behavior. Exclude uremia and drug causes. |
| 8             | Organic brain syndrome      | Altered mental function with impaired orientation, memory, or other intellectual function, with rapid onset and fluctuating clinical features, inability to sustain attention to environment, plus at least two of the following: perceptual disturbance, incoherent speech, insomnia or daytime drowsiness, increased or decreased psychomotor activity. Exclude metabolic, infectious, or drug causes. |
| 8             | Visual disturbance          | Retinal changes of SLE. Include cytoid bodies, retinal hemorrhages, serous exudates or hemorrhages in the choroids, or optic neuritis. Exclude hypertension, infectious, or drug causes.                                     |
| 8             | Cranial nerve disorder      | New onset of sensory or motor neuropathy involving cranial nerves.                                                                                                                                         |
| 8             | Lupus headache              | Severe, persistent headache: may be imgrainous but must be nonresponsive to narcotic analgesia.                                                                                                          |
| 8             | Cerebrovascular accident    | New onset of cerebrovascular accident(s); exclude arteriosclerosis.                                                                                                                                     |
| 8             | Vasculitis                  | Ulceration, gangrene, tender finger nodules, periungual infraction, splinter hemorrhages, or biopsy or angiogram proof of vasculitis.                                                                    |
| 4             | Arthritis                   | Two or more joints with pain and signs of inflammation (i.e., tenderness, swelling, or effusion).                                                                                                          |
| 4             | Myositis                    | Proximal muscle aching/weakness, associated with elevated creatine phosphokinase/aldolase or electromyogram changes or a biopsy showing myositis.                                                       |
| 4             | Urinary casts               | Heme granular or red blood cell casts                                                                                                                                                                    |
| 4             | Hematuria                   | More than five red blood cells/high power field; exclude infection, or other cause.                                                                                                                     |
| 4             | Proteinuria                 | >0.5g/24 hr.                                                                                                                                                                                                |
| 4             | Pyuria                      | More than five white blood cells/high power field; exclude infection.                                                                                                                                     |
| 2             | Rash                        | Inflammatory type rash                                                                                                                                                                                 |
| 2             | Alopecia                    | Abnormal, patchy, or diffuse loss of hair                                                                                                                                                                 |
| 2             | Mucosal ulcers              | Oral or nasal ulcerations                                                                                                                                                                                |
| 2             | Pleurisy                    | Pleuritic chest pain with pleural rub or effusion or pleural thickening.                                                                                                                                  |
| 2             | Pericarditis                | Pericardial pain with at least one of the following: rub, effusion, or electrocardiogram or echocardiogram confirmation.                                                                                   |
| 2             | Low complement              | Decrease in the complement proteins C3 and C4 or in total complement activity (CH50), below the lower limit of normal of testing laboratory.                                                              |
| 2             | Increased DNA binding       | Increased DNA binding by Farr assay above normal range for testing laboratory.                                                                                                                               |
| 1             | Fever                       | >38°C; exclude infectious cause.                                                                                                                                                                           |
| 1             | Thrombocytopenia            | <100,000 platelets/x10⁹/L; exclude drug causes                                                                                                                                                            |
| 1             | Leukopenia                  | <3,000 white blood cells/x10⁹/L; exclude drug causes.                                                                                                                                                     |

Total score

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### APPENDIX 2. SYSTEMIC LUPUS INTERNATIONAL COLLABORATING CLINIC/AMERICAN COLLEGE OF RHEUMATOLOGY DAMAGE INDEX FOR SYSTEMIC LUPUS ERYTHEMATOSUS*

| Item                                                                 | Score |
|----------------------------------------------------------------------|-------|
| **Ocular (either eye, by clinical assessment)**                      |       |
| Any cataract ever                                                    | 1     |
| Retinal change or optic atrophy                                      | 1     |
| **Neuropsychiatric**                                                 |       |
| Cognitive impairment (e.g., memory deficit, difficulty with calculation, poor concentration, difficulty in spoken or written language, impaired performance level) or major psychosis | 1     |
| Seizures requiring therapy for 6 months                             | 1     |
| Cerebrovascular accident ever (score 2 if >1)                        | 1 (2) |
| Cranial or peripheral neuropathy (excluding optic)                   | 1     |
| Transverse myelitis                                                  | 1     |
| **Renal**                                                            |       |
| Estimated or measured glomerular filtration rate <50%                | 1     |
| Proteinuria ≥ 3.5 gm/24 hours                                        | 1     |
| Or End-stage renal disease (regardless or dialysis or transplantation)| 3     |
| **Pulmonary**                                                        |       |
| Pulmonary hypertension (right ventricular prominence, or loud P2)   | 1     |
| Pulmonary fibrosis (physical and radiograph)                         | 1     |
| Shrinking lung (radiograph)                                          | 1     |
| Pleural fibrosis (radiograph)                                        | 1     |
| Pulmonary infarction (radiograph)                                    | 1     |
| **Cardiovascular**                                                   |       |
| Angina or coronary artery bypass                                      | 1     |
| Myocardial infarction ever (score 2 if >1)                           | 1 (2) |
| Cardiomyopathy (ventricular dysfunction)                             | 1     |
| Valvular disease (diastolic, murmur, or systolic murmur > 3/6)       | 1     |
| Pericarditis for 6 months, or pericardiectomy                        | 1     |
| **Peripheral vascular**                                              |       |
| Claudication for 6 months                                           | 1     |
| Minor tissue loss (pulp space)                                       | 1     |
| Significant tissue loss ever (e.g., loss of digit or limb) (score 2 if >1 site) | 1 (2) |
| Venous thrombosis with swelling, ulceration, or venous stasis        | 1     |
| **Gastrointestinal**                                                 |       |
| Infarction or resection of bowel below duodenum, spleen, liver, or g | 1 (2) |
|   wall bladder ever, for cause any (score 2 if >1 site)              |       |
| Mesenteric insufficiency                                             | 1     |
| Chronic peritonitis                                                  | 1     |
| Structure or upper gastrointestinal tract surgery ever               | 1     |
| **Musculoskeletal**                                                  |       |
| Muscle atrophy or weakness                                           | 1     |
| Deforming or erosive arthritis (including reducible deformities, excluding avascular necrosis) | 1     |
| Osteoporosis with fracture or vertebral collapse (excluding avascular necrosis) | 1     |
| Avascular necrosis (score 2 if >1)                                   | 1 (2) |
| Osteomyelitis                                                        | 1     |
| **Skin**                                                             |       |
| Scarring chronic alopecia                                            | 1     |
| Extensive scarring or panniculum other than scalp and pulp space    | 1     |
| Skin ulceration (excluding thrombosis) for >6 months                 | 1     |
| **Premature gonadal failure**                                        | 1     |
| **Diabetes (regardless of treatment)**                               | 1     |
| **Malignancy (exclude dysplasia)(score 2 if >1 site)**               | 1 (2) |

*Damage (nonreversible change, not related to active inflammation) occurring since onset of lupus, ascertained by clinical assessment and present for at least 6 months unless otherwise stated. Repeat episodes must occur at least 6 months apart to score 2. The same lesion cannot be score twice.*
