Systemic Lupus Erythematosus Follow-Up Questionnaire: Paediatric SLE 12 Months After Diagnosis
Australian Paediatric Surveillance Unit

Please contact Dr Fiona Mackie on (02) 9382 1646 or **F.Mackie@unsw.edu.au** if you have any questions about this form

REPORTING CLINICIAN

1. APSU Dr Code/Name: ☐☐☐☐/_____ **2.** Month/Year of Report: ____./_____

3. Date questionnaire completed ☐☐ /☐☐/☐☐

PATIENT DETAILS

4. First 2 letters of first name: ☐☐ **5.**First 2 letters of surname: ☐☐

6. Date of Birth: ☐☐/☐☐/☐☐ **7.** Sex: ☐M ☐F

8. Postcode of family: ☐☐☐☐

Thank you for your questionnaire response received on ☐☐/☐☐/☐☐. **You are receiving this short questionnaire as a follow-up. We are particularly interested in progression of disease, medications used and side effects experienced over the last 12 months since diagnosis. If you are no longer caring for this patient, who can we contact for this information?**

Name: ***Hospital:***

Instructions: Please answer each question by ticking the appropriate box or writing your response in the space provided. DK= Don't Know, NA = Not applicable

Disease progress 12 months since last report

9. When was the child last seen? (Date):☐☐ /☐☐/☐☐

10. Unchanged from initial presentation ☐Yes ☐No ☐DK

11. New symptoms since presentation:

a. Malar rash ☐Yes ☐No ☐DK
b. Discoid rash ☐Yes ☐No ☐DK
c. Photosensitive skin rash ☐Yes ☐No ☐DK
d. Oral ulcers ☐Yes ☐No ☐DK
e. Arthritis ☐Yes ☐No ☐DK
f. Pleuritis ☐Yes ☐No ☐DK
g. Pericarditis ☐Yes ☐No ☐DK
h. Renal disease ☐Yes ☐No ☐DK
i. Proteinuria >3+ or >500mg/day ☐Yes ☐No ☐DK
j. Cellular casts ☐Yes ☐No ☐DK
k. Microscopic haematuria ☐Yes ☐No ☐DK

Most recent creatinine µ mol/L _____ date: ☐☐/☐☐/☐☐

l. Renal biopsy? ☐Yes ☐No ☐DK

Date of biopsy: ☐☐/☐☐/☐☐ If you have a renal biopsy report and are willing to provide, please attach to this questionnaire in a *de-identified form*.

Class of renal disease (*may mark more than 1*): 0 1 2 3 4 5 6

m. Neurological:

Seizures ☐Yes ☐No ☐DK
Psychosis ☐Yes ☐No ☐DK

n. Haematological disorder:

Haemolytic anaemia ☐Yes ☐No ☐DK
Leukopenia (<4000/mm³ total on 2 or more occasions) ☐Yes ☐No ☐DK
Lymphopenia (<1500/mm³ on 2 or more occasions) ☐Yes ☐No ☐DK
Thrombocytopenia (<100,000/mm³ on 2 or more occasions) ☐Yes ☐No ☐DK
Prolonged APTT ☐Yes ☐No ☐DK

o. Current immunological status (not baseline): Tick Yes if positive (abnormal titres) at most recent testing.

Anti-dsDNA IU/mL ☐Yes ☐No ☐DK Most recent titre IU/mL _____
Anti-Sm IU/mL ☐Yes ☐No ☐DK
Antiphospholipid - any ☐Yes ☐No ☐DK
Anti-RNP IU/mL ☐Yes ☐No ☐DK

Anti-Ro IU/mL ☐ Yes ☐ No ☐ DK

Anti-La IU/mL ☐ Yes ☐ No ☐ DK

ANA ☐ Yes ☐ No ☐ DK Most recent titre IU/mL _____

C3 g/L _____ C4 g/L _____ CH100 g/L _____

Other disease or symptoms: _____

12. Medications prescribed since diagnosis

a. Daily Oral Prednisone ☐ Yes ☐ No ☐ DK

b. Cyclosporin ☐ Yes ☐ No ☐ DK

c. Alternate Day Prednisone ☐ Yes ☐ No ☐ DK

d. Tacrolimus ☐ Yes ☐ No ☐ DK

e. Methylprednisone ☐ Yes ☐ No ☐ DK

f. Rituximab ☐ Yes ☐ No ☐ DK

g. Cyclophosphamide ☐ Yes ☐ No ☐ DK

h. Hydroxychloroquine ☐ Yes ☐ No ☐ DK

i. Azathioprine ☐ Yes ☐ No ☐ DK

j. IVIG ☐ Yes ☐ No ☐ DK

k. Mycophenolate ☐ Yes ☐ No ☐ DK

l. Anti-inflammatories ☐ Yes ☐ No ☐ DK

m. Other _____

13. Did any of the following events occur in the last 12 months since initial presentation?

a. Thrombosis ☐ Yes ☐ No ☐ DK

b. Permanent neurological disability ☐ Yes ☐ No ☐ DK If Yes, please specify _____

c. Received blood transfusion ☐ Yes ☐ No ☐ DK

d. Renal failure requiring dialysis ☐ Yes ☐ No ☐ DK

e. Death ☐ Yes ☐ No If Yes, please provide date of death: ☐☐ / ☐☐ / ☐☐

Please return this questionnaire in the addressed reply-paid envelope
Thank you for your help with this research project
Please contact the APSU on (02) 9845 3005 if you have any questions about this form