Systemic Lupus Erythematosus Questionnaire: Paediatric SLE
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
10. Country of birth:____________________________________________________________________________________

If this patient is primarily cared for by another physician whom you believe will report the case and could provide additional details, please write that physician’s name in the space below then complete the questionnaire details above this line and return to APSU. If no other report is received for this child we will contact you for information requested in the remainder of the questionnaire.

The primary clinician caring for this child is: 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

FAMILY DETAILS
11. Mother’s Ethnicity: □ Aboriginal □ Torres Strait Islander □ Caucasian □ Pacific Islander □ Maori □ Middle Eastern
□ Asian □ African □ Latin American □ Indian subcontinent □ Other Please Specify: __________________________
12. Mother’s country of birth: _____________________________________________________
13. Father’s Ethnicity: □ Aboriginal □ Torres Strait Islander □ Caucasian □ Pacific Islander □ Maori □ Middle Eastern
□ Asian □ African □ Latin American □ Indian subcontinent □ Other Please Specify: __________________________
14. Father’s country of birth: _____________________________________________________

PRESENTATION
15. Specialty of treating doctor at initial presentation (e.g. general paediatrician, paediatric rheumatologist, adult immunologist, etc):____________________________

16. Presenting features (tick all that apply)

- Malar rash □ Yes □ No □ DK
- Discoid rash □ Yes □ No □ DK
- Photosensitive skin rash □ Yes □ No □ DK
- Oral ulcers □ Yes □ No □ DK
- Arthritis □ Yes □ No □ DK
- Pleuritis □ Yes □ No □ DK
- Pericarditis □ Yes □ No □ DK
- Serum creatinine µ mol/L __________________
- Seizures □ Yes □ No □ DK
- Psychosis □ Yes □ No □ DK
- 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
- Anti-DNA antibody in abnormal titre □ Yes □ No □ DK Presenting titre IU/ml __________________________
- Anti-SM antibody present □ Yes □ No □ DK Presenting titre IU/ml __________________________
u. Anti phospholipid Ab (IgG or IgM, cardiolipin Ab 2) ☐ Yes ☐ No ☐ DK
v. Lupus anticoagulant positive ☐ Yes ☐ No ☐ DK
w. False positive serological test for syphilis ☐ Yes ☐ No ☐ DK
x. Anti nuclear antibody (ANA) ☐ Yes ☐ No ☐ DK Presenting titre/U/ml: _________________

C3 g/L ________________________ C4 g/L ____________________ CH100 g/L ________________________
y. Fatigue ☐ Yes ☐ No ☐ DK
z. Weight loss ☐ Yes ☐ No ☐ DK
aa. Fevers ☐ Yes ☐ No ☐ DK
bb. Alopecia ☐ Yes ☐ No ☐ DK
c. Myalgia ☐ Yes ☐ No ☐ DK
d. Other _________________________________

Pathology
17. Has this patient had a renal biopsy? ☐ Yes ☐ No ☐ DK
18. Date of biopsy: ☐/☐/☐
19. Classification of renal biopsy: ☐ No nephritis
☐ Class I Minimal mesangial nephritis
☐ Class II Mesangial proliferative lupus nephritis
☐ Class III Focal lupus nephritis
☐ Class IV Diffuse lupus nephritis
☐ Class V Membranous lupus nephropathy
☐ Class VI Advanced sclerosing lupus nephritis
(may mark more than 1 class) If you have a renal biopsy report and are willing to provide a copy, please attach to this questionnaire in a de-identified form.
20. Has this patient had a skin biopsy? ☐ Yes ☐ No ☐ DK
21. Date of biopsy: ☐/☐/☐

23. Medications prescribed since presentation
a. Daily Oral Prednisone ☐ Yes ☐ No ☐ DK/NA
b. Cyclosporin ☐ Yes ☐ No ☐ DK/NA
c. Alternate Day Prednisone ☐ Yes ☐ No ☐ DK/NA
d. Tacrolimus ☐ Yes ☐ No ☐ DK/NA
e. Methylprednisone ☐ Yes ☐ No ☐ DK/NA
f. Rituximab ☐ Yes ☐ No ☐ DK/NA
g. Cyclophosphamide ☐ Yes ☐ No ☐ DK/NA
h. Hydroxychloroquine ☐ Yes ☐ No ☐ DK/NA
i. Azathioprine ☐ Yes ☐ No ☐ DK/NA
j. IVIG ☐ Yes ☐ No ☐ DK/NA
k. Mycophenolate ☐ Yes ☐ No ☐ DK/NA
l. Anti-inflammatories ☐ Yes ☐ No ☐ DK/NA
m. Anticonvulsant ☐ Yes ☐ No ☐ DK/NA
n. Antihypertensive ☐ Yes ☐ No ☐ DK/NA
o. Other :

24. During the first presentation did the patient require:

a. Outpatient management ☐ Yes ☐ No ☐ DK b. Date of outpatient management: ☐/☐/☐
c. Inpatient (ward) admission ☐ Yes ☐ No ☐ DK If yes,
   Date of admission: ☐/☐/☐ Date of discharge: ☐/☐/☐
d. Inpatient (ICU or high dependency) admission ☐ Yes ☐ No ☐ DK If yes,
   Date of admission: ☐/☐/☐ Date of admission: ☐/☐/☐

25. Did any of the following events occur during the first presentation?

a. Thrombosis ☐ Yes ☐ No ☐ DK
b. Permanent neurological disability ☐ Yes ☐ No ☐ DK If Yes, please specify:______________________________
c. Received blood transfusion ☐ Yes ☐ No ☐ DK If Yes, please specify:______________________________
d. Renal failure requiring dialysis ☐ Yes ☐ No ☐ DK

Please return this questionnaire in the addressed reply-paid envelope or by fax on (02) 9845 3082. 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