



Abstract CE-38 Figure 1 PheWas of males vs. females with SLE. "The x axis represents phewas codes that are mapped to ICD-9 codes organized by organ system. The y axis represents the level of significance. Females are the reference group. The lower horizontal line represents the $p < 0.05$ significance threshold. The upper horizontal line represents the Bonferroni threshold. Three codes met the Bonferroni threshold and are indicated above with odds ratio and 95% confidence intervals.

CE-39 LUPUS IN ST. LUCIA

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Background Systemic lupus erythematosus is a chronic, systemic autoimmune disease of unknown cause. It is known to be more prevalent in Afro-Caribbean populations than in Caucasian, however there is little research on this population in the Caribbean. The most recent is "SLE in an African Caribbean population: Incidence, Clinical manifestations, and survival in the Barbados National lupus registry".¹ There is data from Martinique from 1990–1999² and from Curacao 1980–1989.³ The 5 YSR ranged significantly from 60.1% in Curacao to 79.9% in Barbados and 96.4% in Martinique. The population of St. Lucia is 166526 (2010 census) and is of a similar ethnicity to Barbados and Martinique. There is one rheumatologist in St. Lucia. A study of her 131 private patients from 1995–2011 demonstrated a 5 YSR of 97%.⁴ A national study is therefore required.

Materials and methods Patient information will be gathered from the rheumatologist's private clinic as well as from the public health centres and hospitals and from private practitioners and the public. The Ministry of health has agreed to set up a national registry and the rheumatologist is doing "lupus diagnosis and management" training of District Medical officers and Family nurse practitioners (and pharmacists etc.) in June 2016 after which 4 dedicated health practitioners will be apprenticed to her in the public clinic every month. There will be collaboration with the local arthritis and lupus support group and the media will be used to invite lupus patients to register. The rheumatology team will confirm the diagnosis satisfying ACR 1997 or SLICC) and enter data which will be analysed.

Results Preliminary results from the private patient cohort showed 92% Afro-Caribbean, 131 patients- 123 female, 8 male.

Mean age- female 31, male 34. Incidence 6.5 per 100 000. Renal involvement 47%, renal failure 6.1%. Osteoporosis 29%.

Conclusions Lupus epidemiology is similar to Martinique and Barbados, with preliminary findings suggesting a relatively favourable prognosis. Renal failure remains the most common serious complication. Osteoporosis is frequent (on calcaneal ultrasound) and requires further study with an aim of better prevention and management.

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CE-40 LONG-TERM DEVELOPMENT OF AUTOIMMUNE DISEASE IN CHILDREN WITH NEONATAL LUPUS AND THEIR UNAFFECTED SIBLINGS

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Background Several studies have evaluated mortality and short term morbidity in neonatal lupus (NL), however there is minimal data on long term outcomes in children exposed to maternal anti-Ro antibodies in utero. A previous pilot study utilising the Research Registry for Neonatal Lupus (RRNL) raised concern regarding the development of autoimmune disease in childhood,

however the numbers evaluated were small and the patients studied were young. This study was initiated to ascertain the current prevalence of autoimmune disease in NL children and their unaffected siblings, and to evaluate whether fetal or maternal factors associated with the development of future autoimmunity.

Materials and methods A retrospective cohort of family members from the RRNL were contacted to evaluate for autoimmune disease. Follow-up questionnaires were completed which included 35 items describing symptoms and diagnoses associated with autoimmunity in 138 cardiac NL children, 74 cutaneous NL children, and 134 unaffected siblings. Medical records were obtained and evaluated from the patient's physicians to confirm diagnoses. Maternal diagnosis of systemic lupus and/or Sjogren's syndrome and fetal cardiac disease severity based on a previously described severity score were associated with postnatal autoimmune diseases using chi square and Mann-Whitney analyses.

Results Seventeen (8.0%) of NL affected children developed an autoimmune disease at the time of follow up (mean age 11.6 ± 9.0 years). These included 3 patients with SLE, 1 with JIA, 3 with thyroid disease, 5 with psoriasis, 1 with IBD, 1 with uveitis, 1 with UAS and 2 with type 1 DM. Six (4.5%) unaffected siblings developed an autoimmune disease (mean age 10.6 ± 7.1 years), which included 1 with JIA, 1 with Sarcoidosis/ITP, 1 with Myasthenia Gravis/Celiac disease, 1 with psoriasis, 1 with UAS and 1 with type 1 DM. There was a significant association of between having an autoimmune disease and having advanced heart block (11.0% vs. 4.2%, $p = 0.03$) and a trend towards an association with cardiac NL disease severity score (4.43 ± 4.89 vs. 2.58 ± 4.24 , $p = 0.06$). Mother's diagnosis of SLE or Sjogren's did not associate with the children's development of autoimmune disease ($p = 0.828$).

Conclusions Fetuses that develop advanced congenital heart block as a manifestation of NL may be at greater risk for developing autoimmune diseases later in life. This could potentially relate to a genetic component that makes a Ro exposed fetus both more prone to inflammatory effects of passive immunity and predisposes to future autoimmunity, independent of the mother's rheumatic disease status.

CE-41

DISEASE ACTIVITY AND HEALTH CARE UTILISATION AMONG YOUNG ADULTS WITH CHILDHOOD-ONSET LUPUS TRANSITIONING TO ADULT CARE: DATA FROM THE PAEDIATRIC LUPUS OUTCOMES STUDY

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Background Individuals with childhood-onset systemic lupus erythematosus (cSLE) must transfer from paediatric- to adult-oriented health care as they enter adulthood. However, few studies have assessed outcomes of the transition from paediatric to adult care in cSLE. The goal of this study is to examine disease activity and health care utilisation among young adults with cSLE who are undergoing or have recently completed the transition to adult care.

Materials and methods Data derive from the baseline interview of the Paediatric Lupus Outcomes Study, an annual longitudinal telephone survey of 91 diverse English- and Spanish-speaking participants age 18–30 with confirmed cSLE (age of onset <18 years). Subjects were recruited from paediatric and adult rheumatology clinics; diagnosis of cSLE was confirmed by chart review.

Abstract CE-41 Table 1 Demographics, disease characteristics and healthcare utilisation among young adults with cSLE in paediatric rheumatology care vs. young adults with cSLE who have transferred to adult care

	Paediatric rheumatology care (n = 47) N (%) or Mean (SD)	Adult rheumatology care (n = 38) N (%) or Mean (SD)	P
Demographics			
Age (years)	19 (1)	24 (3)	<0.001
Female	41 (87)	36 (95)	NS
Non-white ethnicity	35 (74)	29 (11)	<0.001
Age at diagnosis (years)	13 (3)	13 (2)	NS
Disease Characteristics			
Renal biopsy ever	25 (54)	18 (47)	NS
Cyclophosphamide use ever	7 (15)	19 (50)	<0.001
Disease activity (SLAQ)*	11 (11)	9 (10)	NS
Self-reported flare in the past 3 months	14 (31)	10 (26)	NS
Health Care Utilisation			
Current medications			
Plaquenil	41 (89)	24 (63)	0.005
Steroid	36 (76)	7 (18)	<0.001
DMARD	33 (70)	12 (32)	<0.001
Biologic	0 (0)	0 (0)	NS
Insurance coverage	45 (96)	34 (89)	NS
Difficulty obtaining insurance	5 (11)	13 (34)	0.008
Rheumatology visit in the past year	44 (94)	26 (68)	0.002
General MD visit in the past year	23 (51)	15 (41)	NS
ED visit in the past year	18 (38)	9 (24)	NS
Hospitalization in the past year	14 (30)	9 (24)	NS

*SLAQ = Systemic Lupus Activity Questionnaire (0–47)

To define a cohort undergoing transition from paediatric to adult care, we included respondents who received care from a paediatric rheumatologist currently or in the past (N = 85). We assessed disease activity according to the Systemic Lupus Activity Questionnaire (SLAQ), self-reported SLE flare in the past 3 months, current immunosuppressive medication use (any steroid, DMARD or biologic medication), current health insurance coverage, and health care utilisation over the past year. Bivariate analyses were used to compare individuals cared for by adult rheumatologists to those who continue in paediatric care.

Results Mean baseline age was 21 ± 3 years, and mean age at diagnosis was 13 ± 3 years. Ethnicities included White (48%), Black (5%), Asian (20%), Latino (24%), multi-ethnic (5%) and other (6%). 38 respondents (45%) had transferred care out of paediatric rheumatology (Table 1). Most respondents were currently insured (93%), however those who had transferred were more likely to report difficulty obtaining insurance (34% v. 11%, $p = 0.008$). 32% had visited an emergency department and 27% had received inpatient care in the past year, with similar rates in adult and paediatric care groups. There was no difference in disease activity (SLAQ score 9 v. 11) or likelihood of self-reported