1110 OVERVIEW OF THE CHILDHOOD SYSTEMIC LUPUS ERYTHEMATOSUS (CSLE) COHORT IN THE CARRA REGISTRY

[1]Christine Bacha, [2]Andrea Knight, [3]Laura Schanberg, [4]Mary Beth Son, [5]Emily von Scheven, [6]Aimee Hersh*, for the CARRA Registry Investigators. *[1]Division of Pediatric Rheumatology, Nationwide Children's Hospital; [2]Division of Pediatric Rheumatology, Hospital for Sick Children; [3]Division of Pediatric Rheumatology, Duke University Hospital; [4]Division of Immunology, Boston Children's Hospital; [5]Division of Pediatric Rheumatology, UCSF Benioff Children's Hospital; [6]Division of Pediatric Rheumatology, University of Utah*

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Background The Childhood Arthritis and Rheumatology Research Alliance (CARRA) Registry is a multi-center, observational registry that collects demographic, clinical, and provider- and patient-reported data from patients with pediatric-onset rheumatic diseases in North America, Israel and Italy. This study aimed to describe the demographic features, cumulative clinical manifestations, and treatments of the childhood systemic lupus erythematosus (cSLE) cohort within the CARRA Registry.

Abstract 1110 Table 1 Sociodemographic characteristics of the CARRA cSLE Registry Cohort at enrollment

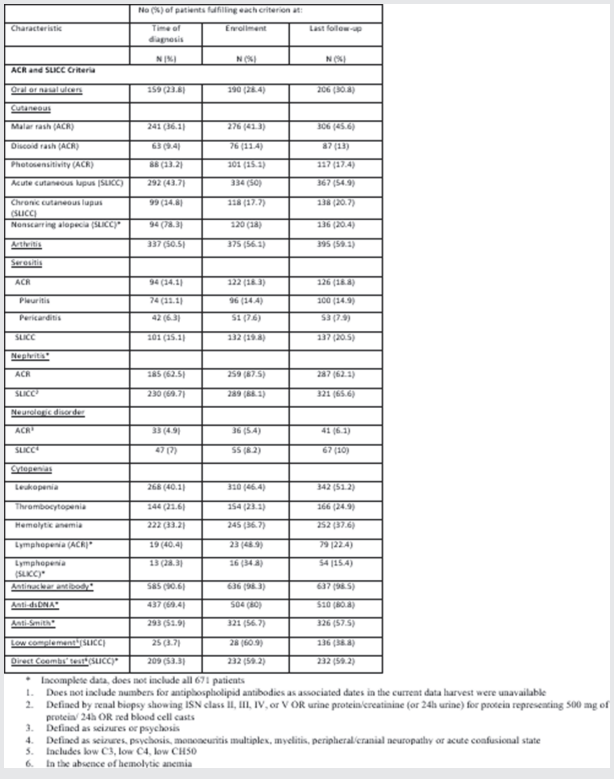
Characteristics	N=671
Gender, n (%)	
Male	99 (14.8)
Female	572 (85.3)
Age at enrollment (years)	
Median	15
Mean (SD)	14.3 (2.9)
IQR	11-15
Race/ethnicity (self-reported), n (%)	
White	175 (26.1)
Black	199 (29.7)
Hispanic	155 (23.1)
American Indian/Alaskan native	8 (1.2)
Asian	99 (14.8)
Middle Eastern/North African	7 (1)
Native Hawaiian/Pacific Islander	3 (0.5)
Other	12 (1.8)
Prefer not to answer/Missing	13 (1.9)
Insurance, n (%)	
Private	312 (46.5)
Public insurance	277 (41.3)
Uninsured	17 (2.5)
Other	65 (9.7)
Income, n (%)	
<25,000	84 (12.5)
25,000-49,999	108 (16.1)
50,000-74,999	62 (9.2)
75,000-99,999	60 (8.9)
100,000-150,000	61 (9.1)
≥ 150,000	64 (9.5)
Prefer not to answer/Unknown	232 (34.6)

IQR, interquartile range

Methods Since 2015, the CARRA Registry has enrolled 10,411 patients at 70 centers. Childhood-onset SLE enrollment began in March 2017. We performed a retrospective cohort study of patients with cSLE enrolled in the US between March 2017 to December 2020. Inclusion criteria for participants in the CARRA cSLE Registry include: 1) diagnosis of cSLE at <18 years based on American College of Rheumatology (ACR) or Systemic Lupus Erythematosus International Collaborating Clinics (SLICC) ; 2) enrollment within two years of cSLE diagnosis or at the time of a flare of lupus nephritis; and 3) enrollment prior to 21 years of age. Sociodemographic and clinical data were summarized using descriptive statistics.

Results The current registry cohort includes 671 participants with cSLE. The majority are female (85%) with mean age at enrollment of 14.3 (SD 2.9) years. The cohort is both ethnically and racially diverse (table 1). Socioeconomic status varies widely, noting 12.5% having a household income below $25,000/year. The median time from symptom onset to diagnosis was two months (interquartile range (IQR) 25 days to 6 months), from diagnosis to enrollment was 5 (IQR 1-15) months, and from enrollment to end of follow up was 14 (IQR 6 to 23) months. At the end of the follow-up period, more than 60% of participants developed nephritis as defined by ACR or SLICC criteria. 6.1% and 10% had neurological manifestations per ACR and SLICC criteria, respectively (table 2). Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) at enrollment was a median of 4 (IQR 2-10). Most patients were prescribed hydroxychloroquine. In the first 2-3 years of disease, participants received a variety of immunosuppressive therapies including Mycophenolate Mofetil, Cyclophosphamide, Azathioprine, Rituximab, Belimumab and disease

Abstract 1110 Table 2 Prevalence of the American College of Rheumatology (ACR) classification Criteria and SLICC Classification Criteria in a cSLE cohort (N=671)



Characteristic	No (%) of patients fulfilling each criterion at: Time of diagnosis N (%)	Enrollment N (%)	Last follow-up N (%)
ACR and SLICC Criteria			
Oral or nasal ulcers	159 (23.8)	190 (28.4)	206 (30.8)
Cutaneous			
Malar rash (ACR)	241 (36.1)	276 (41.3)	306 (45.6)
Discoid rash (ACR)	63 (9.4)	76 (11.4)	87 (13)
Photosensitivity (ACR)	88 (13.2)	101 (15.1)	117 (17.4)
Acute cutaneous lupus (SLICC)	292 (43.7)	334 (50)	367 (54.9)
Chronic cutaneous lupus (SLICC)	99 (14.8)	118 (17.7)	138 (20.7)
Nonscarring alopecia (SLICC)*	94 (78.3)	120 (18)	136 (20.4)
Arthritis	337 (50.5)	375 (56.1)	395 (59.1)
Serositis			
ACR	94 (14.1)	122 (18.3)	126 (18.8)
Pleuritis	74 (11.1)	96 (14.4)	100 (14.9)
Pericarditis	42 (6.3)	51 (7.6)	53 (7.9)
SLICC	101 (15.1)	132 (19.8)	137 (20.5)
Nephritis*			
ACR	185 (62.5)	259 (87.5)	287 (62.1)
SLICC[2]	230 (69.7)	289 (88.1)	321 (65.6)
Neurologic disorder			
ACR[3]	33 (4.9)	36 (5.4)	41 (6.1)
SLICC[4]	47 (7)	55 (8.2)	67 (10)
Cytopenias			
Leukopenia	268 (40.1)	310 (46.4)	342 (51.2)
Thrombocytopenia	144 (21.6)	154 (23.1)	166 (24.9)
Hemolytic anemia	222 (33.2)	245 (36.7)	252 (37.6)
Lymphopenia (ACR)*	19 (40.4)	23 (48.9)	79 (22.4)
Lymphopenia (SLICC)*	13 (28.3)	16 (34.8)	54 (15.4)
Antinuclear antibody*	585 (90.6)	636 (98.3)	637 (98.5)
Anti-dsDNA*	437 (69.4)	504 (80)	510 (80.8)
Anti-Smith*	293 (52.9)	321 (56.7)	326 (57.5)
Low complement*(SLICC)	25 (3.7)	28 (60.9)	136 (38.8)
Direct Coombs' test*(SLICC)*	209 (53.3)	232 (59.2)	232 (59.2)

* Incomplete data, does not include all 671 patients
1. Does not include numbers for antiphospholipid antibodies as associated dates in the current data harvest were unavailable
2. Defined by renal biopsy showing ISN class II, III, IV, or V OR urine protein/creatinine (or 24h urine) for protein representing 500 mg of protein/ 24h OR red blood cell casts
3. Defined as seizures or psychosis
4. Defined as seizures, psychosis, mononeuritis multiplex, myelitis, peripheral/cranial neuropathy or acute confusional state
5. Includes low C3, low C4, low CH50
6. In the absence of hemolytic anemia

Abstract 1110 Table 3 Immunosuppressive treatment in the CARRA cSLE Registry Cohort (N=671)

Medication	Ever Prescribed N (%)	Currently prescribed N (%)
Steroids	614 (83.7)	308 (42)
Oral	569 (77.5)	305 (41.6)
Intravenous	319 (43.5)	15 (2)
Hydroxychloroquine	631 (94)	598 (89.1)
Mycophenolate Mofetil	373 (55.6)	295 (44)
Cyclophosphamide	97 (14.5)	22 (3.3)
Azathioprine	131 (19.5)	81 (12.1)
Rituximab	131 (16.7)	28 (4.1)
Belimumab	32 (4.9)	28 (4.2)
Other[1]	113 (16.8)	60 (8.9)

modifying anti-rheumatic drugs such as Leflunomide and Methotrexate. 84% of patients were prescribed either oral or intravenous glucocorticoids during their disease course (table 3).

Conclusions The CARRA Registry has enrolled a racially and ethnically diverse cohort of cSLE patients in the early course of their disease. These participants exhibit moderate disease activity and although the use of hydroxychloroquine in this cohort is high, a significant proportion of patients are utilizing glucocorticoids at the last study visit. We anticipate enrolling a minimum of 1000 participants with more than ten years of follow-up. This cohort, which is one of the Centers for Disease Control (CDC) funded SLE registries, provides a unique opportunity to describe the natural history, treatments, and outcomes in patients with cSLE.

1111 INCREASING ACCESS AND QUALITY OF CARE FOR INDIVIDUALS FROM UNDERREPRESENTED COMMUNITIES LIVING WITH LUPUS: INSIGHTS FROM QUALITATIVE INTERVIEWS WITH PATIENTS AND PHYSICIANS

[1,2]Saira Z Sheikh*, [3]Maria L Naylor, [3]Lasair O'Callaghan, [3]Lina Sladkeviciute, [3]Janine Gaiha-Rohrbach, [3]Cherie Butts. [1]*University of North Carolina at Chapel Hill, Thurston Arthritis Research Center, Chapel Hill, NC, USA*; [2]*University of North Carolina at Chapel Hill School of Medicine, Department of Medicine, Division of Rheumatology, Allergy and Immunology, Chapel Hill, NC, USA*; [3]*Biogen, Cambridge, MA, USA*

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Background Lupus disproportionately affects Black/African American (AA) and Latino/a patients, yet these underrepresented racial/ethnic minority populations often face challenges with accessing quality care.[1,2] We aimed to explore patients' and physicians' perceptions on the treatment journey for underrepresented patients and identify barriers to quality care.

Abstract 1111 Table 1 Demographics of Patient and Physician Participants

Characteristic, n (%)	Patients[a] (n = 33)	Physicians[a] (n = 20)
Patient age		
18–35 years	4 (12)	NA
36–65 years	26 (79)	NA
66+ years	3 (9)	NA
Female	29 (88)	NA
Race/Ethnicity		
Black/African American	16 (48)	2 (10)
Latino/a	10 (30)	0
Asian/Pacific Islander	5 (15)	4 (20)
Native American	2 (6)	1 (5)
White/Caucasian	0	12 (60)
Prefer not to disclose	0	1 (5)
Region		
Northeast	11 (33)	8 (40)
Midwest	5 (15)	1 (5)
South	12 (36)	8 (40)
West	5 (15)	3 (15)
Education level		
Some high school or less[b]	2 (6)	0
Some college	8 (24)	0
Graduated college/technical school	17 (52)	0
Postgraduate degree	6 (18)	20 (100)
Employment status		
Full time	11 (33)	NA
Part time	4 (12)	NA
Other[c]	18 (55)	NA
Type of lupus		
SLE	23 (70)	NA
CLE	4 (12)	NA
Other[d]	6 (18)	NA
Severity of lupus		
Mild	4 (12)	NA
Moderate	23 (70)	NA
Severe	6 (18)	NA
Physician specialty	NA	
Rheumatology	NA	11 (55)
Dermatology	NA	9 (45)
Investigator vs referring physician		
Referring physician	NA	14 (70)
Investigator	NA	6 (30)
Years experience post-residency		
5–19 years	NA	13 (65)
20+ years	NA	7 (35)
Physician practice: patient race		
Majority Black or African American (> 50% of patients)	NA	7 (35)
Majority White/Caucasian (> 50% of patients)	NA	4 (20)
Mix (all races < 50% of patients)	NA	9 (45)
Physician practice: patient insurance coverage		
Physicians with commerically/privately insured (> 50% of patients)	NA	11 (55)
Physicians with Medicare insured (> 50% of patients)	NA	1 (5)
Physicians with mix (private and Govt insured, all < 50% of patients)	NA	8 (40)

CLE = cutaneous lupus erythematosus; NA = not applicable or data not available; SLE = systemic lupus erythematosus.
[a]Patient participants were recruited from a database of individuals who agreed to be contacted for research purposes. Interviews were conducted between November 2020 and January 2021 (patients) and between December 2020 and February 2021 (physicians).
[b]Includes 1 patient who was currently in school.
[c]Includes on disability (n = 8), retired (n = 4), homemaker (n = 4), unemployed, looking for work (n = 1), and student (n = 1).
[d]Includes both SLE and CLE (n = 3) and unknown/not sure (n = 3).

Methods In-depth qualitative interviews were conducted with patients with lupus from underrepresented populations (Black/AA, Latino/a, Native American, Asian/Pacific Islander) and