Abstract 1118 Table 1 Estimated Number of New Persons Diagnosed with Systemic Lupus Erythematosus in the United States in 2018

	FEMALE				
Race/Ethnicity (Number of sites in analysis)	**SLE Incidence [a]** per 100,000 (95% CI)		**Population Denominator**	**Estimated # SLE Cases in United States** (95% CI)	
Race					
Black (4)	15.9	(12.5, 20.3)	24,880,722	3,956	(3,110, 5051)
White (4)	5.7	(4.9, 6.7)	130,137,989	7,418	(6,377, 8719)
Asian/PI (2)	7.6	(5.5, 10.4)	12,544,896	953	(6,90, 1305)
AI/AN (1)	10.4	(6.6, 14.6)	2,238,966	233	(148, 327)
Total [b]	**8.7**	**(8.1,9.4)**	**169,802,573**	**12,560**	**(10,325, 15,402)**
Ethnicity					
Hispanic [c] (2)	6.8	(6.2, 7.6)	30,689,083	2,087	(1,903, 2332)
	MALE				
	Incidence [a] per 100,000 (95% CI)		**Population Denominator**	**Estimated # SLE Cases in United States** (95% CI)	
Race					
Black (4)	2.4	(1.8, 3.2)	22,961,129	551	(413, 735)
White (4)	0.8	(0.6, 1.1)	127,942,583	1,024	(768, 1,407)
Asian/PI (2)	0.4	(0.2, 0.6)	11,660,533	47	(23, 70)
AI/AN (1)	3.8	(1.6, 7.8)	2,134,870	81	(34, 167)
Total [b]	**1.2**	**(0.9, 1.6)**	**164,699,115**	**1,703**	**(1,238, 2,379)**
Ethnicity					
Hispanic [c] (2)	0.9	(0.4, 1.9)	31,281,605	282	(125, 594)

Systemic lupus erythematosus cases were defined according to the 1997 revised American College of Rheumatology criteria.
[a]Estimates for Blacks and Whites are based on pooled estimates from the four state-based registries; Asian/Pacific Islanders (Asian/PI) and Hispanics are based on pooled estimates from California and New York; American Indian/Alaska Native (AI/AN) estimates are based on the Indian Health Service Registry.
[b]The pooled 'total' incidence estimate includes Black, White and Asian/Pacific Islanders (Asian/PI). Since the American Indian/Alaska Native (AI/AN) incidence was based on one registry and was significantly higher, it was not included in the pooled incidence per 100,000.
[c]Hispanic ethnicity is not mutually exclusive from the race categories, i.e., all Hispanic persons are included in one of the race categories. Thus, the pooled estimates do not incorporate the Hispanic rates since that would lead to duplicate counting. Estimates for Hispanics are based on pooled estimates from California and New York.

Conclusion A coordinated network of population-based SLE registries provided more accurate estimates of the incidence of SLE and the numbers of new individuals affected with SLE in the U.S. in 2018.

1119 RECRUITMENT AND ENROLLMENT INTO A DIRECT-TO-FAMILY PEDIATRIC LUPUS TRIAL

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Background A direct-to-family or virtual approach can improve participant recruitment, retention, and diversity, and improve efficiency of clinical trials. Pediatrics and rare disease may especially benefit from this approach. Recruitment and enrollment of direct-to-family trials in pediatric lupus has not been described. We hypothesize that engaging patients and leveraging a disease registry will facilitate recruitment and enrollment into a direct-to-family pediatric lupus trial (NCT: 04358302).
Objective Evaluate the feasibility of enrolling and recruiting participants into a nationwide, novel direct-to-family pediatric lupus trial
Methods Investigators and study leaders collaborated with patients and advocacy groups, key stakeholders, and a disease registry (Childhood Arthritis and Rheumatology Research Alliance, CARRA Registry) to design a direct-to-family pediatric lupus trial. Participants across the country were identified through the CARRA Registry. Recruitment and informed consent/assent were conducted remotely by a single site (Duke Clinical Research Institute, DCRI).
Results 191 potentially eligible participants were identified through the CARRA Registry. Of the 84 participants who participated in a live discussion, 44 (52%) scheduled a consenting call. The original enrollment goal of 20 participants was met in 10 days. Enrollment was increased to 26, and an additional 18 participants were added to a back-up list due to high interest.
Conclusions Using a single site to recruit and enroll participants into a nationwide direct-to-family pediatric lupus trial was highly feasible, quick, and effective. Recruiting participants from a disease registry and engaging patient advocacy groups were key to successful enrollment.

1120 DETERMINATION OF THE MINIMAL CLINICALLY IMPORTANT DIFFERENCE (MCID) OF THE PHYSICIAN GLOBAL ASSESSMENT (PGA) IN SLE

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Introduction The PGA is a SLE outcome measurement reflecting the physician's assessment of a patient's disease activity. It is considered a 'gold standard' and contributes to responder indices for clinical trials, as well as to definitions of the low lupus disease activity state (LLDAS) and remission. Although a few studies have evaluated its sensitivity to change, no studies have assessed its minimal clinically important difference (MCID). Our objective was to determine the MCID of the PGA using prospective data collected in a single center.
Methods PGAs were scored prospectively by 3 physicians on consecutive patient visits; the difference between a visit PGA and the previous visit's PGA was the ΔPGA. A disease flare visit was defined as a visit in which therapy was increased (initiation or increase of corticosteroid dose and/or DMARD or biologic agent). We constructed a receiver operating characteristics (ROC) curve to visualize the performance of the ΔPGA for predicting flare and determined the MCID of the PGA for flare using an anchored approach by calculating Youden's index for the ΔPGA in 0.1 increments.
Results Data from 129 patient visits with ΔPGA and therapeutic decisions (therapy increase/flare or therapy decreased or no change/no flare) were available. The baseline PGA was between 0- 0.9 in 79 visits, 1.0-1.9 in 38 visits and between 2.0-3 in 12 visits. Flare occurred in 85 visits while no flare occurred in 44 visits with 43 (50.6%) of flares occurring with a baseline PGA between 0-0.9, 30 (35.3%) with a baseline PGA between 1-1.9 and 12 (14.1%) flares with a baseline