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# Delays to care in pediatric lupus patients from the Childhood Arthritis and Rheumatology Research Alliance Legacy Registry

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## Abstract

**Objectives—**Prompt treatment for lupus is important to prevent morbidity. A potential barrier to early treatment of pediatric lupus is delayed presentation to a pediatric rheumatologist. To better understand factors contributing to delayed presentation among pediatric lupus patients, we examined differences in demographic and clinical characteristics of lupus patients within the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Legacy Registry with regards to time between symptom onset and presentation to a pediatric rheumatologist.

**Methods—**We analyzed data from 598 CARRA Legacy Registry participants for differences between those who presented early (within <1 month of symptom onset), between 1–3 months (typical presentation), with moderate delays (3–12 months), and with severe delays (≥1 year). Factors associated with early presentation, moderate delay, and severe delay, were determined by multinomial logistic regression.

**Results—**Forty-four percent of patients presented early, while 23% had moderate delays and 9% had severe delays. Family history of lupus, absence of discoid rash and location in a state with a higher density of pediatric rheumatologists was associated with earlier presentation. Younger age, low household income (<$25,000 per year), and a family history of lupus were associated with severe delay.

**Conclusions—**Delays to care ≥ 1 year exist in a notable minority of pediatric lupus patients from the CARRA Legacy Registry. In this large and diverse sample of patients, access to care and family resources played an important role in predicting time to presentation to a pediatric rheumatologist.

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## INTRODUCTION

Early detection and treatment is thought to be critical to prevent morbidity and improve outcomes in both adults (1–3) and children (4, 5) with lupus. While the time to diagnosis for lupus patients has improved over the past several decades (6), significant delays still exist (7). Prompt management may be challenging for patients with rheumatologic diseases given widespread shortages in rheumatology practitioners and the difficulty in recognizing and diagnosing many of these relatively rare disease entities (8–10). Delayed diagnosis and presentation to a rheumatologist has been described worldwide in some of the most common adult rheumatologic diseases, such as rheumatoid arthritis (11) and psoriatic arthritis (12), as well as the more common pediatric rheumatologic diseases, such as juvenile idiopathic arthritis (13–15).

Diagnosing rheumatologic diseases in children and quickly connecting them to specialist care is likely more challenging than in adults. Shortages of pediatric subspecialists are more profound than of adult subspecialists (16). Recent examination of a pediatric lupus cohort from the United Kingdom shows a wide range of presentation time, with some patients enduring severe delays of greater than a year (17). However, contributing factors to delays in care are still poorly understood and have not been well investigated in other large or diverse cohorts around the globe.

In this study, we aimed to examine factors associated with delays to the first pediatric rheumatology visit of pediatric lupus patients enrolled in the Childhood Arthritis and Rheumatology Research Alliance (CARRA) Legacy Registry, a large and diverse cohort of pediatric lupus patients from North America. Evaluating disparities in delays to care is an important initial step toward identifying ways to overcome barriers to equitable care and improve outcomes for all pediatric lupus patients.

## PATIENTS AND METHODS

### Study population

Data from the CARRA Legacy Registry for pediatric lupus were examined. The Legacy Registry was the initial phase of the CARRA Registry and included 62 sites in North America and most pediatric rheumatology centers in the United States. Pediatric lupus patients were included in the registry if they had been diagnosed with systemic lupus erythematosus (SLE) by a pediatric rheumatologist before the age of 18 and enrolled in the registry before the age of 21, to capture childhood-onset SLE and standardize the definition of pediatric patients across the sites. Data were collected from the inception of the CARRA Legacy Registry in May 2010 through November 2013. Research personnel entered data electronically at each CARRA site. De-identified demographic and clinical data from baseline registry visits were analyzed. Approval for exemption was obtained from the Einstein-Montefiore Institutional Review Board for this study.

Analysis included 598 of the total 988 SLE patients in the registry who were confirmed to have met 1997 Revised American College of Rheumatology (ACR) SLE classification criteria (18) and who had precise data for date of symptom onset and first visit with a

pediatric rheumatologist (Figure 1). Demographic data was obtained from participant and parent completed questionnaires. Family medical history, date of symptom onset and date of first presentation to a pediatric rheumatologist were obtained from provider questionnaires, completed using information from the family and verified by medical records. Estimated dates were provided for most patients when exact dates were not available, while 5% (54) of patients in the registry had neither precise nor estimated data for symptom onset or for first rheumatology visit. To try to maintain the most accurate data, only those participants with exact dates were used in our analysis. From these data, the time between symptom onset to presentation to a pediatric rheumatologist was calculated.

Demographic information included household income, insurance status, and three-digit zip-code prefixes for the zip-codes corresponding to where participants were located at symptom onset. All registry patients in the analysis were from the United States, including Puerto Rico. Three-digit zip-code prefixes were matched to US states and territories based on the United States Postal Service data. To define states that had a low density of pediatric rheumatologists, state-level data from a previously published Health Resources and Services Administration workforce report of the number of pediatric rheumatologists per population under 18 (19) was used to determine whether states were below or at and above the median density (1 pediatric rheumatologist per 443,800 children).

## Statistical analysis

Statistical analysis was performed using Stata 14 (StataCorp, College Station, Texas). The time to the first pediatric rheumatology visit was categorized as <1 month (early presentation), 1–3 months (typical presentation), 3–12 months (moderate delay), and ≥1 year (severe delay). The cut-off for early presentation of ≤1 month was chosen based on prior studies that defined patients with “acute onset lupus” as those that were diagnosed within one month (20). Of non-early presenters meeting ACR SLE criteria from the CARRA Registry, approximately half of the cohort was seen within 3 months and were therefore defined as “typical presenters.”

Variable data were examined for normality and nonparametric tests were used when applicable. Kruskal-Wallis tests were used for nonparametric continuous variables across the categories of presentation time, while Wilcoxon rank sum tests were used for pairwise comparisons. Pearson’s chi-square tests and Fisher’s exact tests were used to compare categorical variables across different categories of presentation time and for pairwise comparisons. Cuzick nonparametric tests for trend were used to examine trends across the groups from typical presenters to severely delayed. The four categories of presentation time were compared in a multivariable multinomial logistic regression model, where the typical presentation (1–3 months) was set as the reference group and factors with $p<0.25$ from the univariable analysis were included. Statistical significance was set to be $p<0.05$.

# RESULTS

## Patient characteristics

The final analysis sample in this present study included 598 patients who met ACR SLE classification criteria and had precise data on the times of symptom onset and first pediatric rheumatology visit from the total 998 SLE patients in the CARRA Legacy Registry (Figure 1). Compared to the 598 patients, the excluded patients (either due to missing data on precise times of symptom onset or first rheumatology visit, missing data for ACR SLE criteria, or not meeting criteria) were more likely to be from low income households, to have become symptomatic in a state with a low density of pediatric rheumatologists, and to have lower SLE Disease Activity Indices (SLEDAIs) at their first registry visit. The characteristics of the 598 included patients are summarized in Table 1. Overall, the median age of onset was 13 years (IQR 11, 15), 83% were female, 75% identified as minority race and/or ethnicity; 16% were from low income households (while 36% of the total cohort reported unknown on income or deferred to answer) and 28% were from states with low densities of pediatric rheumatologists when they first became symptomatic.

Median time between onset of symptoms and first seeing a pediatric rheumatologist was 1.4 months (IQR 7 days, 3.6 months) for included participants. Among them, 262 (44%) were seen in ≤1 month, 145 (24%) between 1–3 months, 137 (23%) between 3–12 months, and 54 (9%) in ≥1 year.

## Comparisons of patient characteristics across categories of delay

We compared demographics (Table 1) and clinical characteristics (Table 2) across categories of presentation times to see a pediatric rheumatologist. Age at onset ($p=0.0003$), location in a state with a low density of pediatric rheumatologists ($p=0.009$), SLE family history ($p=0.02$), and proportions of patients meeting immunologic ACR SLE classification criteria ($p=0.03$) were significantly different across the different levels of delay to presentation. SLEDAI scores were lower, but not significantly, in patients who presented latest. Variables with $p<0.25$ were included in the subsequent multivariable analysis.

Examining trends across the groups from typical presentation to severe delays, age of onset decreased with each level of delay (trend test, $p=0.001$), as did the likelihood of meeting immunologic ACR SLE classification criteria (trend test, $p=0.04$), while the likelihood of coming from a low-income household increased (trend test, $p=0.01$).

## Multivariable multinomial logistic regression model

The multivariable multinomial logistic regression model used typical presentation (1–3 months) as the reference group and included the following independent variables: age of onset, household income, location in a state with a low density of pediatric rheumatologists, family history of SLE, having discoid rash, arthritis, immunologic criteria, and neurologic ACR SLE classification criteria, and having proliferative lupus nephritis.

**Factors contributing to early presentation to a pediatric rheumatologist—**Table 3 shows the comparison between early presenters and typical presenters from the

multivariable multinomial logistic regression model. Compared to the reference group of patients presenting between 1–3 months, patients with a family history of SLE were more likely to present in <1 month (odds ratio (OR) 3.1, 95% confidence interval (CI) 1.0–9.4, p=0.04). Patients who lived in a state with a low density of pediatric rheumatologists or met criteria for discoid rash were less likely to present early (OR 0.6, 95% CI 0.3–0.9, p=0.02; OR 0.5, 95% CI 0.2–1.0, p=0.04, respectively).

**Factors contributing to moderate and severe delays in presentation to a pediatric rheumatologist—**Table 4 shows a comparison between moderately and severely delayed presenters and typical presenters from the same multivariable multinomial logistic regression model. Patients with proliferative lupus nephritis were less likely to present with moderate delays (3–12 months) compared to typical presentation (OR 0.6, 95% CI 0.3–1, p=0.048). No other significant factors were noted in this comparison. Severe delays were associated with younger age of onset (OR 0.8, 95% CI 0.7–0.9, p<0.001), low household income (<$25,000 annual income vs ≥$25,000; OR 2.8, 95% CI 1.1–7.0, p=0.03), and a family history of SLE (OR 4.1, 95% CI 1.1–16.1, p=0.04).

## DISCUSSION

While most lupus patients in the CARRA Legacy Registry were seen by a pediatric rheumatologist within 3 months of symptom onset, moderate delays of 3–12 months were seen in 23% of patients, and severe delays of ≥ 1 year were noted in 9%. Contributing factors to these delays are likely complex and multifactorial. While individual clinical characteristics may influence how quickly patients come to attention or how expedited a referral is made, our data show that family and household characteristics, as well as accessibility to a pediatric rheumatologist, additionally play an important role.

In this study, earlier age of symptom onset was seen in patients with severe delays to care. Perhaps in younger children, lupus was less easily recognized and therefore, took longer to present to a pediatric rheumatologist. However, compared to adults, pediatric patients present with more fulminant, severe disease (21) and more often present with renal and neurologic manifestations (22, 23). Many may require hospitalization, leading to more immediate contact with a specialist. This may explain why overall, a shorter median time to presentation was seen here in comparison to adult lupus cohorts (7, 24).

Studies in adult lupus have examined accrual time, defined as the time from which a patient develops a single ACR SLE criterion to the time at least 4 are met to satisfy diagnostic criteria. Accrual time in adult lupus patients is shortened in males (25) and “acute onset lupus,” defined as disease with accrual time within one month, is associated with renal involvement and worse disease activity (20). Similar to this study, adult patients with discoid rash are less likely to present early (20, 24).

However, in contrast to these adult studies, our results suggest that early presentation to a pediatric rheumatologist (<1 month) may not be as strongly driven by disease severity. While we found that patients with moderate delays were less likely to have proliferative lupus nephritis than typically presenting patients (patients seen in 1–3 months); in

multivariable testing, neither proliferative lupus nephritis, nor renal manifestations in general, were associated with the earliest presenters. Neurologic manifestations, another marker of severe disease, also lacked an association with early presentation.

In a sensitivity analysis, we redefined early presentation as <2 weeks and defined severe lupus by the presence of ACR neurologic criteria and/or proliferative lupus nephritis to see if this was associated with early presentation. Neither decreasing the defining time for early presentation nor combining renal and neurologic criteria to define severe disease changed our results. Furthermore, disease activity measured by SLEDAI was not significantly different across presentation times, nor was it different for earlier presenters compared to typical presenters. Finally, because SLEDAI measurements were taken at first registry visit and not at initial presentation, in a post-hoc analysis we examined worst ever ACR functional class status for registry patients, with the consideration that many patients' worst ever functional status would be upon disease presentation. We found that despite a pattern of lower proportions of patients who had ever met class IV (most severely impaired) ACR functional status with each level of delay (p trend=0.002), ACR functional status was not a significant predictor for any level of delay (or for early presentation) in the multivariable regression model.

These results differ from a smaller study of pediatric lupus patients from Croatia, in which disease activity was inversely correlated to diagnosis time (26) and a study in the UK in which patients with lupus nephritis were more quickly diagnosed (17). However, since our study examined time to presentation to a pediatric rheumatologist and not diagnosis, this difference may be a result of some ill and acutely presenting patients being first diagnosed and treated by other specialists such as nephrologists, immunologists, or adult rheumatologists. In a recent survey of pediatricians from a geographically underserved section of the US, over a third of respondents reported that they had referred children to adult rheumatologists because of either long travel distances or long wait times to see a pediatric rheumatologist (27). This problem may be exacerbated in the future, by projected worsening shortages in the US pediatric rheumatology workforce over the next decade (28).

Interestingly, a family history of lupus was predictive of both the earliest and latest presenters. The association with early presentation can be more easily explained, perhaps because parents and providers were more likely to recognize the diagnosis and families may have already had relationships with rheumatologists. The association with late presenters was unexpected. It may be that these patients were more likely to first be seen by an adult rheumatologist, especially if the family was already connected to one. Alternatively, perhaps the challenges of caring for lupus within a family inhibited more prompt presentation times for an additional family member. While poverty was not associated with a family history of lupus, there may be other environmental stressors that confound the relationship between a family history of lupus and delayed presentation.

Important findings from this study are the demographic associations observed in the earliest and latest presenters. A smaller proportion of early presenters were from a state with a low density of pediatric rheumatologists, and a larger proportion of the latest presenters were from low-income households. This indicates that access to care and family resources may

play a significant role in determining the time it takes a child with lupus to see a pediatric rheumatologist.

This is an important distinction from findings from the previous studies from the UK and Croatia, in which no association was found between time to see a rheumatologist and distance to a pediatric rheumatologist or socioeconomic level (17). It must be noted that the UK and Croatia are smaller in area than many states within the US and that distances patients traverse may not vary as much as they may in the US. Furthermore, density of rheumatologists may be a more sensitive marker for whether an area is underserved because it may capture wait times, possibly a more difficult barrier to overcome than distance. In regards to the lack of association with socioeconomic level in the European studies, one possible explanation for this is differences in health care delivery across economic backgrounds in the US in comparison to other countries (29). In contrast, our findings support a wealth of research on the importance of demographic and socioeconomic disparities when it comes to care of lupus patients in the US, where patients with poor healthcare access and low income have worse outcomes (30, 31).

Limited accessibility to pediatric rheumatology specialists in the United States has been well described. About a quarter of the pediatric population in the US live further than 80 miles from the nearest pediatric rheumatologist (32); pediatric rheumatologists are highly concentrated in urban metropolitan areas (16). But access is complex and relates not only to geography, volumes in subspecialty clinics, and wait times. Factors within specific health systems such as referral patterns likely play a role. Additionally, family resources, transportation access, and income all influence how easily a family can travel and take time off from work for visits.

One limitation to this study is the reliance on retrospective data available through family report and chart review for the date of onset of symptoms to determine time to presentation to a pediatric rheumatologist. For the registry database, this information was collected through provider questionnaires. Inherent in this design is a potential for inaccuracy in reporting. To rely on the most accurate information, we limited this analysis to those registry participants who had known specific dates for symptom onset and first pediatric rheumatology visit and excluded those with estimated dates. Potential for bias in this study includes missing data not at random, highlighted by the fact that patients included and excluded in the analysis had important differences in demographics; a large portion of the cohort had missing data on income. Analyses including and excluding participants with income categorized as “deferred or unknown” did not significantly change the overall results in terms of factors associated with delay, and low income remained a significant predictor for severe delay.

Further selection bias may exist, if for instance, healthier patients are more likely to agree to participate in the registry. However, >50% of patients included in the analysis met ACR SLE renal criteria, within the range of what has been described in other pediatric lupus cohorts in North America (23, 33). In addition, 18% had severely impaired functioning at some point in their illness, meeting ACR functional class IV criteria. These both speak to the significant disease burden in the patients that were included in this study.

As has been pointed out in other studies examining diagnostic delays, the time from symptom onset to diagnosis, and ultimately treatment, comprises several intermediate events (11, 13). These include the recognition of symptoms by the family, visit to a primary care provider, time to referral to a specialist, and time between referral and specialist appointment or even, in cases, time between missed appointments to a successfully attended appointment with a specialist. While the data used in this study were not granular enough to pinpoint which steps in this process were most affected, they suggest that household stressors, such as poverty, can lead to delays in the process, as a whole.

The strength of this study is in the large and diverse sample of patients from which data was collected through the CARRA Legacy Registry. Thus, we believe the data is representative of the experience of pediatric lupus patients in the US and that it sheds light on the importance of improving care delivery to children living in poverty and in areas with decreased access to pediatric rheumatology. Changes to healthcare access and worsening shortages of pediatric rheumatologists in the US may be future hurdles for these patients, and may profoundly impact their care. Further identification of specific barriers in between symptom development and presentation to a pediatric rheumatologist may lead to interventions that minimize severe delays for pediatric lupus patients and improve outcomes.

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## SIGNIFICANCE AND INNOVATIONS

- Among pediatric lupus patients enrolled in the CARRA Registry, early presentation (<1 month from symptom onset) to a pediatric rheumatologist was associated with location in a state with a high density of pediatric rheumatologists, a family history of lupus, and the absence of discoid rash.
- Severe delays to care (≥ 1 year) were associated with younger age of onset, a family history of lupus, and low income.

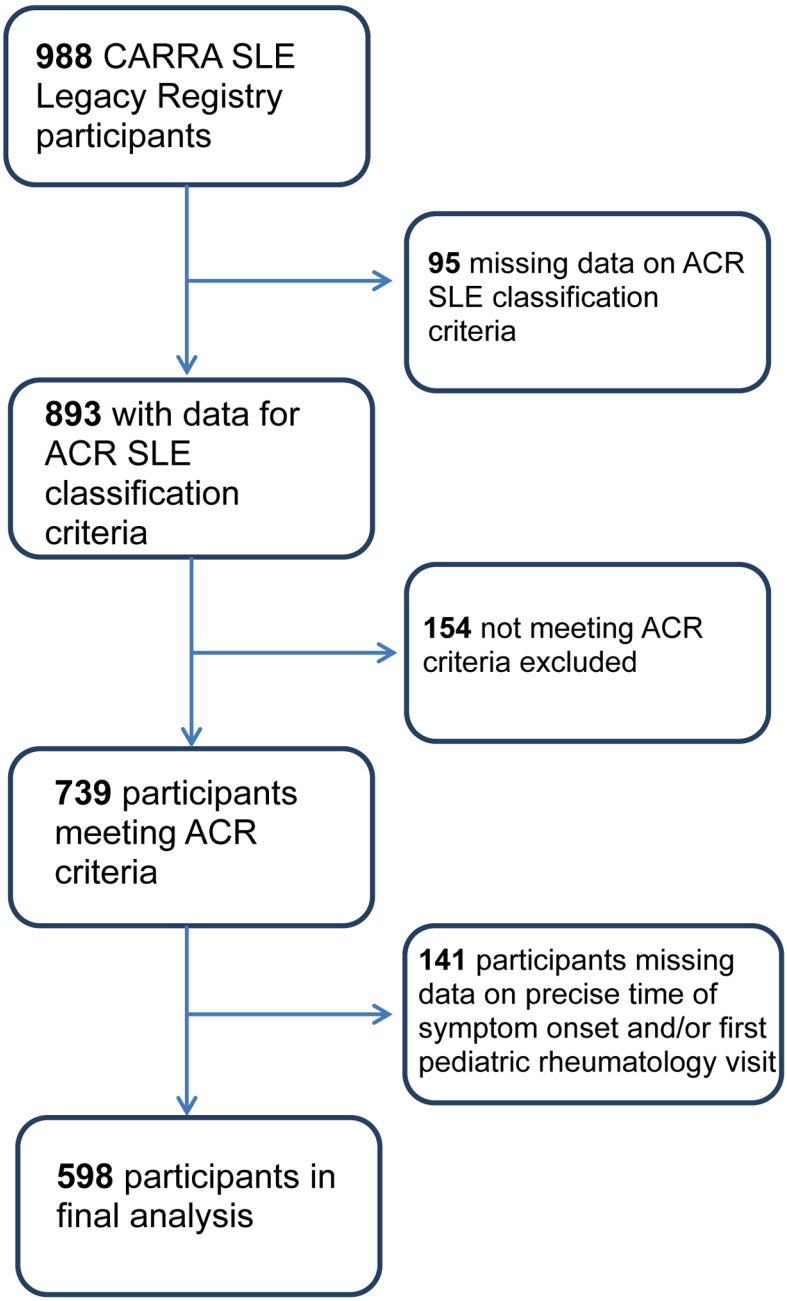


**Figure 1.**
Participants included in secondary data analysis or CARRA SLE Legacy Registry

**Table 1**

Demographic characteristics for patients in the CARRA Lupus Legacy Registry by category of delay to first visit with a pediatric rheumatologist

| | Time to first visit with a pediatric rheumatologist | | | | | |
|---|---|---|---|---|---|---|
| **Demographic characteristics:** | **Total (n = 598)** | **<1 month (n = 262)** | **1–3 months (n = 145)** | **3–12 months (n = 137)** | **≥1 year (n = 54)** | **p value** |
| **Age at symptom onset, median (IQR)** | 13 (11, 15) | 13 (11, 15) | 13 (11, 15) | 13 (11, 15) | 11 (8, 14) [a] | 0.0003 |
| **Female** | 499 (83%) | 214 (82%) | 121 (84%) | 119 (87%) | 45 (83%) | 0.63 |
| **Race/ethnicity** | | | | | | 0.71 |
| **White, non-Hispanic** | 147 (25%) | 58 (22%) | 36 (25%) | 37 (27%) | 16 (30%) | |
| **Black, non-Hispanic** | 172 (29%) | 76 (29%) | 43 (42%) | 39 (29%) | 14 (26%) | |
| **Hispanic** | 161 (27%) | 72 (28%) | 38 (26%) | 38 (28%) | 11 (24%) | |
| **Asian** | 68 (11%) | 31 (12%) | 14 (10%) | 13 (10%) | 10 (19%) | |
| **Other** | 50 (8%) | 25 (10%) | 14 (10%) | 10 (7%) | 1 (2%) | |
| **Household income** * | | | | | | 0.21 |
| **Low (<$25,000)** | 96 (16%) | 43 (16%) | 17 (12%) | 21 (15%) | 15 (28%) | |
| **Other (≥$25,000)** | 287 (48%) | 129 (50%) | 74 (51%) | 63 (22%) | 21 (39%) | |
| **Unknown/deferred** | 215 (36%) | 90 (34%) | 54 (25%) | 53 (26%) | 18 (33%) | |
| **Uninsured** | 23 (4%) | 10 (4%) | 4 (3%) | 5 (4%) | 4 (8%) | 0.53 |
| **Located in underserved state** ** | 152 (28%) | 51 (21%) [b] | 42 (33%) | 45 (37%) | 14 (31%) | 0.009 |
| **SLE family history** | 53 (9%) | 25 (10%) | 5 (4%) [c] | 15 (11%) | 8 (15%) | 0.02 |

*Annual household income in US dollars.

**Located in a state that had less than the median density of pediatric rheumatologists per pediatric population at the time of symptom onset.

Missing data: household income (n=2), insurance status (n=22), located in underserved state (n=62).

[a] $p<0.05$ between the group with ≥1 year and each of the remaining three groups.

**Table 2**

Clinical characteristics for patients in CARRA Lupus Legacy Registry by category of delay to first visit with a pediatric rheumatologist

| | | Time to first visit with a pediatric rheumatologist | | | | |
|---|---|---|---|---|---|---|
| **ACR classification criteria/clinical characteristics:** | **Total(n = 598)** | **<1 month(n = 262)** | **1–3 months(n = 145)** | **3–12 months(n = 137)** | **≥1 year(n = 54)** | **p value** |
| **Malar rash** | 309 (52%) | 130 (50%) | 73 (50%) | 75 (55%) | 31 (57%) | 0.62 |
| **Discoid rash** | 64 (11%) | 21 (8%) | 20 (14%) | 19 (14%) | 4 (7%) | 0.14 |
| **Photosensitivity** | 118 (20%) | 55 (21%) | 28 (19%) | 25 (18%) | 10 (19%) | 0.92 |
| **Arthritis** | 86 (14%) | 31 (12%) | 24 (17%) | 26 (19%) | 5 (9%) | 0.14 |
| **Oral ulcers** | 63 (24%) | 63 (24%) | 32 (22%) | 25 (18%) | 11 (20%) | 0.60 |
| **Serositis** | 110 (18%) | 47 (18%) | 26 (18%) | 25 (18%) | 12 (22%) | 0.90 |
| **Renal** | 309 (52%) | 136 (52%) | 78 (54%) | 69 (50%) | 26 (48%) | 0.89 |
| **Neurologic** | 44 (7%) | 27 (10%) | 9 (6%) | 6 (4%) | 2 (4%) | 0.12 |
| **Hematologic** | 429 (72%) | 190 (73%) | 99 (68%) | 100 (73%) | 40 (74%) | 0.76 |
| **Immunologic** | 559 (94%) | 250 (95%) [a] | 139 (96%) [b] | 122 (89%) | 48 (88%) [c] | 0.03 |
| **ANA** | 584 (98%) | 257 (98%) | 14 (97%) | 133 (97%) | 53 (98%) | 0.90 |
| **Renal biopsy** | 244 (41%) | 110 (42%) | 64 (44%) | 52 (38%) | 18 (33%) | 0.47 |
| **Proliferative disease** [*] | 176 (30%) | 84 (32%) | 47 (32%) | 32 (23%) | 13 (24%) | 0.20 |
| **SLEDAI, median (IQR)** [**] | 4 (0,8) | 4 (1, 8) | 4 (2, 7) | 4 (0, 8) | 2 (0, 6) | 0.78 |

[*] Proliferative disease determined by World Health Organization Lupus Nephritis Classification: class III and class IV.

[**] Systemic Lupus Erythematosus Disease Activity Index (SLEDAI) score at first registry visit.

[a] p<0.05 between the group with <1 month to first visit with a pediatric rheumatologist and each of the remaining three groups.

[b] p<0.05 between 1–3 months and 3–12 months.

[c] p<0.05 between ≥1 year and each of the remaining three groups.

## Table 3

Multivariable results for factors associated with early presentation to a pediatric rheumatologist in the CARRA Lupus Legacy Registry

| | Early presentation (<1 month) | | |
|---|---|---|---|
| | **OR** | **95% CI** | **p value** |
| Age at onset | 1.0 | 0.9, 1.1 | 0.65 |
| Household income * | | | |
| Low (<$25,000) vs. ≥$25,000 | 1.3 | 0.7, 2.6 | 0.43 |
| Unknown/deferred vs. ≥$25,000 | 1.0 | 0.6, 1.7 | 0.87 |
| Located in underserved state ** | **0.6** | **0.3, 0.9** | **0.02** |
| SLE family history | **3.1** | **1.0, 9.4** | **0.04** |
| Discoid ACR SLE criteria | **0.5** | **0.2, 1.0** | **0.045** |
| Arthritis ACR SLE criteria | 0.6 | 0.3, 1.2 | 0.17 |
| Neurologic ACR SLE criteria | 1.5 | 0.7, 3.4 | 0.33 |
| Immunologic ACR SLE criteria | 0.7 | 0.2, 2.2 | 0.50 |
| Proliferative lupus nephritis ǂ | 0.9 | 0.6, 1.5 | 0.76 |

Odds ratios (OR), 95% confidence intervals (CI) and p values are results from the multivariable multinomial logistic regression model. Listed in the table is the comparison between early presenters (<1 month) and the reference group of patients presenting from 1–3 months.

* Annual household income in US dollars.

** Located in a state that had less than the median density of pediatric rheumatologists per pediatric population at the time of symptom onset.

ǂ Proliferative disease determined by World Health Organization Lupus Nephritis Classification: class III and class IV.

**Table 4**

Multivariable results for factors associated with moderate and severe delay to a pediatric rheumatologist in the CARRA Lupus Legacy Registry

| | Moderate delay (3–12 months) | | | Severe delay (≥ 1 year) | | |
|---|---|---|---|---|---|---|
| | **OR** | **95% CI** | **p value** | **OR** | **95% CI** | **p value** |
| Age at onset | 1.0 | 0.9, 1.1 | 0.67 | **0.8** | **0.7, 0.9** | **<0.001** |
| Household income * | | | | | | |
| Low (<$25,000) vs. ≥$25,000 | 1.5 | 0.7, 3.1 | 0.34 | **2.8** | **1.1, 7.0** | **0.03** |
| Unknown/deferred vs. ≥$25,000 | 1.1 | 0.6, 1.9 | 0.81 | 1.2 | 0.5, 2.6 | 0.74 |
| Located in underserved state ** | 1.2 | 0.7, 2.1 | 0.47 | 1.0 | 0.5, 2.1 | 0.92 |
| SLE family history | 2.6 | 0.8, 8.5 | 0.13 | **4.1** | **1.1, 16.1** | **0.04** |
| Discoid ACR SLE criteria | 1.0 | 0.5, 2.1 | 1.00 | 0.5 | 0.1, 1.7 | 0.25 |
| Arthritis ACR SLE criteria | 1.3 | 0.7, 2.6 | 0.47 | 0.4 | 0.1, 1.3 | 0.12 |
| Neurologic ACR SLE criteria | 0.6 | 0.2, 1.7 | 0.31 | 0.3 | 0, 2.4 | 0.25 |
| Immunologic ACR SLE criteria | 0.3 | 0.1, 1.0 | 0.06 | 0.4 | 0.1, 1.8 | 0.24 |
| Proliferative lupus nephritis ǂ | **0.6** | **0.3, 1.0** | **0.048** | 0.7 | 0.3, 1.5 | 0.32 |

Odds ratios (OR), 95% confidence intervals (CI) and p values are results from the multivariable multinomial logistic regression model. Listed in the table is the comparison between early presenters (<1 month) and the reference group of patients presenting from 1–3 months.

* Annual household income in US dollars.

** Located in a state that had less than the median density of pediatric rheumatologists per pediatric population at the time of symptom onset.

ǂ Proliferative disease determined by World Health Organization Lupus Nephritis Classification: class III and class IV.