

**Abstract CE-14 Table 1** Incidence Rates and Hazard Ratios (HR) for associations between SLE and death according to cohort

|           | SLE status | N      | Deaths | Mean follow-up (years) | Incidence rate<br>(per 1000 person-years) | Age, sex and entry-time<br>matched IRR (95% CI): | Fully adjusted HR (95% CI): |
|-----------|------------|--------|--------|------------------------|---|--|-----------------------------|
| Overall   | Yes        | 5,304  | 821    | 4.65                   | <b>33.28</b>                              | 3.56 (3.23, 3.93)                                | <b>2.80 (2.49, 3.16)</b>    |
|           | No         | 15,912 | 836    | 5.63                   | 9.34                                      | 1.00   | 1.00                        |
| Female    | Yes        | 4,521  | 611    | 4.81                   | <b>28.11</b>                              | 3.60 (3.21, 4.03)                                | 2.77 (2.41, 3.18)           |
|           | No         | 13,563 | 603    | 5.69                   | 7.82                                      | 1.00   | 1.00                        |
| Male      | Yes        | 783    | 210    | 3.75                   | <b>71.52</b>                              | 3.80 (3.14, 4.59)                                | 2.95 (2.33, 3.75)           |
|           | No         | 2,349  | 233    | 5.27                   | 18.84                                     | 1.00   | 1.00                        |
| 1997–2004 | Yes        | 1,656  | 334    | 3.00                   | <b>67.33</b>                              | 5.91 (4.96, 7.06)                                | <b>3.95 (3.24–4.83)</b>     |
|           | No         | 5,022  | 209    | 3.65                   | 11.39                                     | 1.00   | 1.00                        |
| 2005–2012 | Yes        | 3,630  | 287    | 3.04                   | <b>25.98</b>                              | 3.59 (3.03, 4.26)                                | <b>2.41 (2.01–2.89)</b>     |
|           | No         | 10,890 | 262    | 3.33                   | 7.23                                      | 1.00   | 1.00                        |

**Conclusions** This population-based study shows that survival of SLE patients has improved over the past decade, suggesting that new treatments and improved management of the disease and its complications may be providing substantial benefits.

#### CE-15 ESTIMATED PREVALENCE OF SYSTEMIC LUPUS ERYTHEMATOSUS (SLE) IN BROOKLYN, NEW YORK, A BOROUGH WITH A LARGE MINORITY AND UNDERSERVED POPULATION

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**Background** Although major improvements in morbidity and mortality have occurred over the last half century, lupus remains a chronic disease with many unmet needs. Using an evidence based approach to identifying the efficacy of new therapeutic modalities, one must conduct randomised clinical trials with rigorous attention to design. Epidemiologic studies of SLE indicate clearly that there are both racial/ethnic and socioeconomic differences in pathophysiology, clinical outcome, and response to therapy. The target population for future trials must include significant representation from minority and disadvantaged patients. Brooklyn, with its rich diversity of racial/ethnic and socioeconomic communities, is an ideal environment for this goal. We therefore sought to assess the overall prevalence of SLE in Brooklyn, identifying the sociodemographic characteristics of its varied neighbourhoods and health care centres.

**Materials and methods** To estimate the overall prevalence of diagnosed SLE in Brooklyn, we used 2015 population statistics derived from Truven Health Analytics, Inc. Data is supplied for each zip code in Brooklyn, specified by race/ethnicity (White non-Hispanic, Black non-Hispanic, Asian non-Hispanic,

Hispanic, and all others), gender, and age (0–14, 15–17, 5-year groups from age 18–64, and >65). Data for each zip code included household income and educational level. To calculate the expected number of SLE patients residing in each zip code, we extrapolated from recent age-standardised prevalence rates by race and gender from the CDC-sponsored Manhattan Lupus Surveillance Study (presented at American College of Rheumatology Annual Meeting, November 2015).

**Results** Based on 2015 population statistics, there are an estimated 1515 adult SLE patients residing in Brooklyn (Table 1). The Bedford-Stuyvesant and Bushwick neighbourhoods have a heavy concentration of African Americans, with the West Indian community including individuals predominantly from Jamaica, Haiti, and Guyana located largely in Canarsie, Flatbush, and East Flatbush. Asian Americans, mostly Chinese, tend to settle in Southern Brooklyn, while immigrants from Arab countries are concentrated in BayRidge in southwest Brooklyn, and Eastern European and Soviet immigrants in the Coney Island, Brighton Beach, and Sheepshead Bay areas. There is a strong overlap between the predicted high neighbourhood prevalence of SLE and Brooklyn's economically disadvantaged neighbourhoods.

**Conclusions** Identifying the Brooklyn neighbourhoods with a high prevalence of SLE patients of specific sociodemographic groups will allow us to plan culturally relevant educational programs to target their needs and encourage participation in research studies including randomised clinical trials.

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#### CE-16 THE PREVENTION, SCREENING, AND TREATMENT OF CONGENITAL HEART BLOCK FROM NEONATAL LUPUS: A SURVEY OF PROVIDER PRACTICES

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**Background** There are presently no official guidelines about the prevention, screening, and treatment of congenital heart block (CHB) due to maternal Ro antibodies. The objective of this study was to survey an international sample of providers to determine their current practices.

**Abstract CE-15 Table 1** Estimated number of SLE patients, age 16–65, residing in Brooklyn, 2015

|        | White | Black | Hispanic | Asian | Total |
|--------|-------|-------|----------|-------|-------|
| Female | 259   | 709   | 269      | 126   | 1364  |
| Male   | 17    | 85    | 32       | 16    | 151   |
| TOTAL  |       |       |          |       | 1515  |

**Materials and methods** A survey was designed by the organising committee of the 9th International Conference of Reproduction, Pregnancy and Rheumatic Diseases. It was sent to 330 people who were prior or current attendees of the conference or authors of recent publications or abstracts at ACR 2012, 2013, or 2014 on rheumatic diseases and pregnancy. Missing demographic information led to exclusion from analysis (n = 11).

**Results** There were 48 respondents. Most (55%) follow >15 pregnancies in rheumatic patients per year, and 33% were practicing rheumatologists for >15 years. Most were university-based physicians (88%) and from North America (42%) or Europe (42%).

**Screening** In anti-Ro/SSA positive women, 80% recommended serial fetal ECHOs, with most starting at gestational week 16 (59%) and stopping at week 28 (25%), although the time to stop varied widely. For women without a prior infant with neonatal lupus, respondents recommend every other week (44%) or weekly (28%) fetal ECHOs. For women with a prior infant with neonatal lupus, 80% recommend weekly fetal ECHOs.

**Prevention** Hydroxychloroquine was recommended by 67% of respondents to prevent CHB and most would start pre-pregnancy (62%).

**Treatment** Respondents were asked about medications for varying degrees of CHB in a 20-week pregnant, anti-Ro and La positive SLE patient. Respondents recommended dexamethasone (53%) or HCQ (43%) for 1<sup>st</sup> degree HB; dexamethasone (88%) for 2<sup>nd</sup> degree HB; and dexamethasone (55%), IVIg (33%), or no therapy (27%) for complete HB. When dexamethasone was started for 2nd degree CHB, 58% would stop dexamethasone if it progressed to complete heart block, 47% would stop if heart block disappeared, and 24% would stop if the 2nd degree CHB remained.

**Conclusions** Despite the absence of official guidelines, many physicians with a clinical focus on pregnancy and rheumatic disease have developed similar patterns in the screening, prevention, and treatment of CHB. These include serial fetal ECHOs, preventive HCQ, and treatment of early heart block with dexamethasone. These practices are not uniform, however, and have not been formally tested in prospective trials. The next step in this field must include testing of these approaches to identify the most cost effective and efficacious plan for these pregnancies.

CE-17

#### A COMMUNITY-ACADEMIC PARTNERSHIP EDUCATING HISPANICS/LATINOS AS POPULAR OPINION LEADERS (POLs) TO INCREASE AWARENESS ABOUT LUPUS

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**Background** A community-university partnership was developed to address lupus disparities in the Hispanic/Latino Chicagoland community. Lupus significantly impacts Latinos due to lack of early detection, diagnosis, and care. A curriculum was created to educate Popular Opinion Leaders (POLs) as leaders who then

**Abstract CE-17 Table 1** Characteristics of groups and knowledge acquisition for POLs in Chicago, IL

| Group characteristics                         | Erie (community health workers, n = 14) | Cicero (teens, n = 14)           | Burbank (adults, n = 28)         |
|---|---|----------------------------------|----------------------------------|
| Birthplace (%)                                | Mexico 64%<br>US 14%<br>Other 21%       | Mexico 14%<br>US 86%<br>Other 0% | Mexico 100%<br>US 0%<br>Other 0% |
| >5 yrs living in US (%)                       | 71%                                     | 100%                             | 100%                             |
| Strong Sense of Community (% highest ratings) | 69%                                     | 79%                              | 82%                              |
| <b>Knowledge of lupus</b>                     | <b>Pre-test post-test</b>               | <b>Pre-test post-test</b>        | <b>Pre-test post-test</b>        |
| Chronic Disease (%yes)                        | 86% 100%                                | 29% 93%                          | 96% 100%                         |
| Cure (%no)                                    | 75% 93%                                 | 21% 86%                          | 56% 81%                          |
| Correct Symptom (%yes)                        | 62% 77%                                 | 71% 100%                         | 80% 88%                          |

provide lupus education to the community. POLs were trained in three local communities; the POL groups consisted of 1) High School Students, 2) Community Health Workers, and 3) Parent Leaders. Our goal was to pilot test this education program across different age groups and literacy levels as a prelude to field work increasing lupus awareness in the targeted communities.

**Materials and methods** To measure knowledge acquisition of the newly trained POLs, pre- and post-test questionnaires were administered over four sessions. Questionnaires were designed with a health literacy expert for content, clarity and literacy level. As part of the assessment, we also analysed the following demographic and acculturation variables: birthplace (Mexico/U.S./Other); # of years in the US; strong sense of belonging to an ethnic group (4-point scale) and the following lupus knowledge variables: lupus is a chronic disease (Yes/No/don't know); there is a cure for lupus (Yes/No/don't know); and which symptom is not a lupus symptom (choose from a list). Demographic and acculturation characteristics and knowledge responses pre- and post-test responses were summarised by community using descriptive statistics.

**Results** We trained community health workers from Erie Neighbourhood House (n = 14), high school students from Cicero (n = 14) and parent leaders from Burbank (n = 28). Participant characteristics and knowledge gain are shown in Table 1.

**Conclusions** Overall, there was evidence to support lupus knowledge improvement after the completion of POL educational sessions. We encountered some difficulties in performing this evaluation due language difficulty not only limited to literacy level but also in interpretation of questions and bilingual interpreters were needed to assist POL assessments. The next phase is to document the community contacts reached by POLs in the field using Geographic Information System (GIS) mapping.