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Disclosures

• Nothing to disclose.
Definitions

- **Prevalence**: proportion of the population with a disease at a given time point (%)
- **Incidence**: rate at which new cases occur in a population in a given time period
  - e.g. rate per 100,000 people per year

- **Prevalence = Incidence x Duration**
  - For diseases with short duration (such as infection), prevalence ≈ or < incidence
  - For diseases with long duration (such as SLE), prevalence > incidence
Systemic Lupus Erythematosus (SLE)

• Autoimmune disease
• Hallmark is autoantibodies in blood
  – Antibodies directed against self
  – Anti-nuclear antibodies (ANA) most common
• Can affect multiple different organ systems
  – Diverse presentations, evolve over time
• Prognosis varies by organ involvement and severity
SLE in Populations

• US population rates
  – Prevalence: 15-144 per 100,000
  – Incidence: 1.8-23.2 per 100,000 per year

• Highest rates in women and US blacks
  – 10:1 female:male ratio
  – Rates up to 5 times higher in blacks than whites
  – Prevalence in black women: 58-286 per 100,000

SLE in indigenous North American populations

• Prevalence of SLE 2x higher than expected in 2 regional studies
  – Manitoba: 42.3 per 100,000 (vs. 20.6)
  – Southeast Alaska: 112.2 per 100,000 (vs. 51.0)

• Incidence of SLE estimated using hospital discharge records from IHS in the 1970s-80s
  – Mean annual incidence ranged from 1.2-4.1
  – Varied by region/tribe

Objective

• This population-based registry was created with the objective to determine the prevalence (2007) and incidence (2007-2009) of SLE in the Indian Health Service (IHS) active clinical population in 3 regions of the US.

• Using comparable methodology to 4 other CDC-funded registries in order to compare rates by race and ethnicity.
Methods

- Denominator
  - IHS active clinical population in 2007 (prevalence) and 2007-2009 (incidence)
    - 2 or more visits to IHS-funded clinic in past 3 years, at least one to a core medical clinic
  - Residing in a community of interest for the registry
    - Communities in Alaska, Phoenix, and Oklahoma City
      - Areas of IHS where rheumatology services available as direct care
Methods

• Potential case ascertainment
  – Identified from the IHS National Data Warehouse
  – Using ICD-9 codes associated with SLE and related connective tissue disorders
  – Database populated with demographic information

• Field medical record abstraction
  – For all potential cases in the database
  – Data elements necessary for verification of SLE classification criteria
  – Trained abstractors with QC protocol
Case Definitions

• Primary:
  – 4 or more of the 11 American College of Rheumatology (ACR) classification criteria for SLE documented in the medical record

• Alternate:
  – Included individuals meeting the primary definition, plus those with 3 ACR criteria and the treating rheumatologist’s final diagnosis of SLE
**Flowchart for inclusion of potential cases**

- **Alaska Region Denominator**
  - n = 117,964
  - Potential cases for chart abstraction n = 395
    - Cases not validated n = 257
      - Prevalent 2007* n = 130
    - Validated cases n = 138
      - Incident 2008-2009 n = 8

- **Phoenix Region Denominator**
  - n = 70,311
  - Potential cases for chart abstraction n = 347
    - Cases not validated n = 213
      - Prevalent 2007* n = 125
    - Validated cases n = 134
      - Incident 2008-2009 n = 9

- **Oklahoma Region Denominator**
  - n = 23,641
  - Potential cases for chart abstraction n = 349
    - Cases not validated n = 317
      - Prevalent 2007* n = 30
    - Validated cases n = 32
      - Incident 2008-2009 n = 2

**Total number of prevalent cases in 2007 = 285**

*Incident cases from 2007 were counted in the number of prevalent cases in 2007 (n = 8 for Alaska, 6 for Phoenix, and 1 for Oklahoma City Area)*
## Prevalence of SLE in 2007*

<table>
<thead>
<tr>
<th>Region</th>
<th>Primary Definition</th>
<th>Alternate Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Unadjusted (95% CI)</td>
<td>Age-adjusted (95% CI)</td>
</tr>
<tr>
<td><strong>Combined</strong></td>
<td>134 (120-151)</td>
<td>178 (157-200)</td>
</tr>
<tr>
<td><strong>Sex-specific</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>215 (190-244)</td>
<td>271 (238-307)</td>
</tr>
<tr>
<td>Male</td>
<td>36 (26-50)</td>
<td>54 (36-77)</td>
</tr>
<tr>
<td><strong>Regional</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alaska</td>
<td>110 (93-131)</td>
<td>149 (124-177)</td>
</tr>
<tr>
<td>Phoenix</td>
<td>178 (149-212)</td>
<td>248 (204-297)</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>127 (89-179)</td>
<td>138 (93-200)</td>
</tr>
</tbody>
</table>

*per 100,000 population; age-adjustment to 2000 projected US population using 10 year age groups.
Age-specific prevalence of SLE by primary case definition

Women

Men

Prevalence (per 100,000)

Age category (years)

Alaska  Oklahoma  Phoenix  Overall

Alaska  Oklahoma  Phoenix  Overall
### Mean annual incidence of SLE, 2007-2009*

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<tr>
<td>Combined</td>
<td>5.9 (4.2-8.0)</td>
<td>7.4 (5.1-10.4)</td>
</tr>
<tr>
<td><strong>Sex-specific</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8.4 (5.8-11.8)</td>
<td><strong>10.4 (6.6-14.6)</strong></td>
</tr>
<tr>
<td>Male</td>
<td>2.7 (1.3-5.2)</td>
<td>---</td>
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<tr>
<td><strong>Regional</strong></td>
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<tr>
<td>Alaska</td>
<td>4.8 (2.9-7.5)</td>
<td><strong>6.1 (3.4-10.2)</strong></td>
</tr>
<tr>
<td>Phoenix</td>
<td>8.1 (5.0-12.6)</td>
<td><strong>10.7 (6.2-17.5)</strong></td>
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<td>Oklahoma</td>
<td>4.3 (1.1-11.7)</td>
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*per 100,000 person-years; total number of incident cases = 38; age-adjustment to 2000 projected US population using 10 year age groups.
Comparison to US blacks in Georgia (GLR) and Michigan (MILES) registries

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<th>MILES age-adjusted rate in blacks</th>
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<td>271 (238-307)</td>
<td>196 (183-210)</td>
<td>186 (179-193)</td>
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<td>54 (36-77)</td>
<td>24 (19-29)</td>
<td>19 (17-22)</td>
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<td>13.4 (11.5-15.6)</td>
<td>12.8 (11.1-14.8)</td>
</tr>
<tr>
<td>Men</td>
<td>2.7 (1.3-5.2)*</td>
<td>3.2 (2.3-4.5)</td>
<td>2.1 (1.3-3.0)</td>
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By primary definition, ≥ 4 ACR criteria documented; IHS incidence in men is not age-adjusted.
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By primary definition, ≥ 4 ACR criteria documented; IHS incidence in men is not age-adjusted.
Conclusions

• The prevalence and incidence of SLE are high in the IHS active clinical population of AI/AN people in 3 regions.
  – Prevalence: 178 per 100,000
  – Incidence: 7.4 per 100,000 person-years

• The prevalence of SLE in AI/AN women in the population included in our registry is comparable to the rate in black women.
  – 271 per 100,000
Indian Health Service Lupus Registry

CDC-funded registries:
- MILES (Michigan)
- GLR (Georgia)
- MLSP (Manhattan)
- CLSP (California)