The international registry is composed of uniform clinical data and biospecimens collected from 9 participating research sites*, and is available to scientists all over the world, with the intent of improving understanding and treatment of Sjögren’s syndrome. *University of Buenos Aires (UBA); Peking Union Medical College Hospital (PUMC); Rigshospitalet (CUHG); Kanazawa Medical University (KMU); Aravind Eye Hospital (AEH); Kings College London Dental Institute (KCI); Johns Hopkins University (JHU); University of California, San Francisco (UCSF); University of Pennsylvania (UPenn)

Sjögren’s International Collaborative Clinical Alliance (SICCA)

The SICCA comprises a group of clinical and laboratory investigators from around the world who have developed the International Sjögren's Syndrome Biorepository and Data Registry.

The registry includes clinical data and biospecimens from individuals with:
- Primary Sjögren’s Syndrome (pSS)
- Secondary Sjögren's Syndrome (sSS)-with associated Rheumatoid Arthritis (RA) or Systemic Lupus Erythematosus (SLE) diagnosed by the American College of Rheumatology (ACR) criteria
- Symptoms of pSS or sSS

In addition, clinical data and biospecimens are available from unrelated controls and family members of participants meeting the SICCA working standard for pSS or sSS.

Available data and biospecimens include:

<table>
<thead>
<tr>
<th>Biospecimens</th>
<th>Clinical Data*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peripheral blood mononuclear cells (PBMC), plasma, serum</td>
<td>Case status</td>
</tr>
<tr>
<td>Saliva – parotid and whole</td>
<td>Race/ethnicity</td>
</tr>
<tr>
<td>Tears</td>
<td>Age and gender</td>
</tr>
<tr>
<td>RNA ocular imprints</td>
<td>Labial salivary gland biopsy diagnosis and focus score</td>
</tr>
<tr>
<td>DNA</td>
<td>Ocular staining focus score</td>
</tr>
<tr>
<td>Labial salivary gland biopsy – paraffin-embedded and frozen glands</td>
<td>Serology – negative or positive (SSA, SSB, ANA, rheumatoid factor)</td>
</tr>
</tbody>
</table>

*Additional clinical data variables may be available.

How to apply for clinical data and biospecimens?

Interested parties should visit the SICCA website and submit a letter of intent. Once approved, the investigator can submit a full application. Applications are reviewed 3 times per year. For complete instructions and types of clinical data and biospecimens available please visit the website at: https://siccaonline.ucsf.edu/

The International Sjögren's Syndrome Biorepository and Data Registry is funded by National Institute of Dental and Craniofacial Research (NIDCR grant U01DE028891)

The SICCA Biospecimen / Data Registry is directed and managed by Dr. Caroline Shiboski from the University of California, San Francisco (UCSF). Web: https://siccaonline.ucsf.edu/

USCS Contact:
Annie Chou, Project Director
(415) 502-7052
Annie.Chou@ucsf.edu

NIDCR Contact:
Preethi Chander, PhD
Director, Salivary Biology and Immunology Program
Division of Extramural Programs
National Institute of Dental and Craniofacial Research, National Institutes of Health
Phone: (301) 827-4620
E-mail: Preethi.Chander@nih.gov

Revised 02/2022