



Sjögren's International Collaborative Clinical Alliance



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:

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

*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/>

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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/>

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