

The Sjögren's disease biobank and registry in NSW

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Abstract

Sjögren's disease (SjD) is a common systemic autoimmune disease that causes dryness symptoms, fatigue and pain. There are currently no targeted therapies available to treat this disorder. As a valuable resource to address this unmet need, the Western Sydney Sjögren's Syndrome Biobank (WS3B) was established in 2021 to promote the understanding, research and health outcomes of SjD in New South Wales and Australia. Five years on, the WS3B has contributed substantially to local, national and international research efforts.

Letter to Editor

Dear Editor,

Autoimmune diseases result when the body's immune system fails to properly distinguish self from non-self, creating a misguided attack on otherwise healthy tissues. Examples of these include type 1 diabetes mellitus, lupus, and Sjögren's disease (SjD). SjD is one of the most common systemic autoimmune diseases, classically resulting in profound dryness symptoms, pain, fatigue and organ damage (Lee et al. 2023b). The disease was named after a Swedish ophthalmologist, Henrik SC Sjögren, who was one of the first to describe the condition in the 1930s (Jonsson 2021). SjD patients are typically middle-aged females and experience a significant impact on their emotional, functional and social health (Lee et al. 2026; Lin et al. 2025). Immunologically, B cell dysregulation and autoantibodies are hallmark features and patients are at high risk of developing B cell cancers (Lee et al. 2023b). Unfortunately, there are currently no cures or targeted therapies for SjD and



patients globally, although several are in trial (Pelkas et al. 2025).

To address these unmet needs in SjD care and research in Australia, I established the Western Sydney SjD Biobank (WS3B) at Westmead Hospital in 2021. This is the first of its kind in Sydney and one of the very few in Australia. The WS3B is a biobank and registry of carefully curated SjD patients and controls. I acknowledge my colleagues, the support of Westmead Hospital and Westmead Institute for Medical Research, and the generous financial support from the Leece Family and Western Sydney Local Health District for facilitating the development and growth of this valuable resource. I am also incredibly grateful to my own patients for

helping advance the knowledge and understanding of SjD in Australia and globally.

The key aims of the WS₃B include:

- To improve the understanding and diagnosis of SjD in Sydney and, in particular, Western Sydney;
- To promote research, teaching and education in SjD in New South Wales and Australia; and
- To improve health outcomes for people living with SjD in New South Wales and across Australia, by advancing precision medicine approaches and developing better therapies.

Now at its 5-year anniversary, the WS₃B has over 100 patients and has contributed to local, national and international studies. These have ranged from basic science to clinical and epidemiology-based projects. Some of the key contributions of the WS₃B include improving the phenotype of SjD patients to facilitate predictive medicine (Lee et al. 2023a), and characterising the impact that one's heritage has on disease manifestations (Lin et al. 2025).

Plans are underway to form a coordinated national SjD research movement. It is hoped that the WS₃B will be an indispensable resource for future and current clinicians and researchers in New South Wales and beyond.

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References

- Jonsson R (2021) Henrik Sjögren (1899–1986): the syndrome and his legacy. *Annals of the Rheumatic Diseases* 80(9): 1108–1109.
- Lee AYS, Putty T, Lin M-W, et al. (2023a) Isolated anti-Ro52 identifies a severe subset of Sjögren's syndrome patients. *Frontiers in Immunology* 14: 1115548.
- Lee AYS, Wang JJ, Gordon TP, et al. (2023b) Phases and natural history of Sjögren's Disease: a new model for an old disease? *Arthritis Care & Research* 75(7): 1580–1587.
- Lee AYS, Zembrzuska H, Franke KB, et al. (2026) Patients' perspectives of living with Sjögren disease: a systematic review of qualitative studies from the OMERACT Sjögren disease working group. *Seminars in Arthritis and Rheumatism* 77: 152929.
- Lin MW, Volk S and Lee AYS (2025) Primary Sjögren disease patients of Asian and Middle Eastern ancestry have early-onset but similar disease activity. *Internal Medicine Journal* 55(5): 856–859.
- Pelkas C, Franke KB, Vincent FB, et al. (2025) Novel therapies in Sjögren's disease: A systematic review of the literature. *Best Practice & Research Clinical Rheumatology* 39(4): 102084.

