



# Lupus registry

## Development of the Australian Lupus Registry

### A RESEARCH PROJECT PLAIN LANGUAGE SUMMARY

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**Institution:** Centre for Inflammatory Diseases, Southern Clinical School, Monash University

**Grant:** \$70,000

**Project timeline:** 2012-2017

Arthritis and Osteoporosis Victoria (now *Musculoskeletal Australia*) provided infrastructure support over six years to the development and expansion of Australia's first lupus registry: the *Australian Lupus Registry* at Monash University.

#### Background

There is currently no specific, effective treatment for lupus in Australia supported by the Pharmaceutical Benefits Scheme (PBS).

Attempts to develop targeted therapies have not been successful. Although many genes associated with lupus have been identified, the biomarkers (or biological markers) that relate to specific aspects of the disease – eg organ involvement, severity of the disease, response to treatment – have been more difficult to pin down.

Without a specific treatment, many people with lupus live with uncontrolled disease activity and will often experience harmful side effects caused by the use of a broad range of medications designed to suppress the immune system (immunosuppressive medications).

Complicating research into lupus is the lack of international agreement on clinical activity or response to treatment. Unlike other inflammatory diseases like rheumatoid arthritis, there is no agreed system in use to define treatment goals, such as remission. This means that there is no agreed or proven treatment target for use in clinical trials or clinical practice.

The *Australian Lupus Registry* is an attempt to gather information and gain some clarity about this complex disease. It will provide data for research and will progress knowledge and solutions to the significant problems encountered by people with lupus.

#### What is lupus?

Systemic lupus erythematosus (SLE) is a chronic condition that results from a malfunctioning immune system. The immune system is designed to identify foreign bodies (such as bacteria and viruses) and attack them to keep us healthy. However, in the case of lupus, the immune system mistakenly attacks particular tissues including the skin, joints, kidneys and lining of the heart and lungs, causing ongoing inflammation and pain.

Women in their child-bearing years are most likely to develop lupus. Nine times more women have lupus than do men. Certain ethnic groups are also more likely to develop lupus, such as Australian Aboriginals, African-American women and Asians. However, lupus can affect men, children and older people.

## **The project**

Clinicians at Monash University/Monash Medical Centre have been collecting serum samples, DNA, as well as matching clinical and laboratory information from patients attending a specific lupus clinic since 2007. This collection of data - past, present and into the future - will create a data bank of information providing unique insights into the long-term health of people with lupus.

Other Australian and international lupus researchers have seen the value of the Monash lupus data collection model and are working with researchers at Monash to extend this work to establish a national lupus registry, or the Australian Lupus Registry.

A national, electronic registry of this type will facilitate large-scale, clinical research, with the initial focus being disease and treatment outcomes. The project is expected to have international relevance and will be of substantial benefit to the Asia-Pacific region.

The steps involved in this long-term project are:

1. create an online database that will collect lupus specific data from multiple locations,
2. add existing lupus data to the database,
3. ongoing long-term collection and
4. early analysis of effectiveness of the database.

In addition, this work has engaged collaborators from 11 countries in the Asia-Pacific region, where lupus is both common and severe, in an effort to define a new way to measure responses to treatment in lupus..

## **Findings**

The Australian Lupus Registry is an ongoing project. It has already resulted in some noteworthy findings.

Researchers have identified links between certain immune system proteins, known as cytokines, and kidney and brain lupus. This may enable more targeted treatment in the future.

They have also made a number of useful findings that will provide clinicians with a greater understanding of lupus, disease activity and response to treatments, including:

- changes in lupus patient blood cell behavior,
- ethnic differences in lupus severity,
- associations between low vitamin D and lupus severity,
- differences between patient- and doctor-assessed disease activity,
- associations between steroid use and organ damage,
- and new potential markers of disease severity in the blood.

This information, and information that will be collected as the Australian Lupus Registry continues, will contribute significantly to what is known about this complex disease..

## **Future research**

Researchers plan to build on the findings of this project and apply for grants to continue studying this area, in partnership with **Arthritis and Osteoporosis Victoria**. One area of future research is to test an intervention package – involving education, equipment and strategies - that will improve access and comfort for people with musculoskeletal conditions when driving or using public transport.

## **Articles**

You can find out more about the Australian Lupus Registry by accessing the many articles that have been written to date. See over page for details.

## **Ongoing developments**

Keep an eye on our website to remain informed on the progress of this, and other research projects supported by Musculoskeletal Australia.

## Articles

1. Vincent F, Morand EF, Mackay F. 2012 BAFF and innate immunity: new therapeutic targets for systemic lupus erythematosus. *Immunology & Cell Biology* 90:293-303.
2. Vincent F, Bourke P, Morand EF, Mackay F, Bossingham D. 2013. Focus on systemic lupus erythematosus in Indigenous Australians: towards a better understanding of autoimmune diseases. *Internal Medicine Journal*, 43 (3), pp. 227-234.
3. Cheng Q, Hoi A, Hickey MJ, Morand EF. 2012 Lymphocytes from systemic lupus erythematosus patients display increased spreading on VCAM-1, an effect associated with active renal involvement. *Lupus*, 21 (6), pp. 632-641.
4. Connelly K, Hoi A, Morand EF. Asian ethnicity in systemic lupus erythematosus: an Australian perspective. *Internal Medicine Journal*, 43 (6), pp. 618-624.
5. Mandana Nikpour, Chak Sing Lau, Sandra V. Navarra, Worawit Luthrenoo, Aisha Lateef, Laniyati Hamijoyo, C. Singgih Wahono, Shun Le Chen, Ou Jin, Alberta Hoi, Eric F. Morand. Preliminary consensus definition of a low disease activity state in systemic lupus erythematosus. *World Lupus Congress*, Argentina, April 2013.
6. Vincent FB, Northcott M, Hoi A, Mackay F and Morand EF. Association of serum B cell activating factor from the tumour necrosis factor family (BAFF) and a proliferation-inducing ligand (APRIL) with central nervous system and renal disease in systemic lupus erythematosus. *Lupus*, 22 (9), pp. 873-884.
7. Golder V, Hoi A, Staples M, Morand EF. Association of Asian ethnicity with disease activity in SLE: an observational study from the Monash Lupus Clinic. *Lupus*, 22 (13), pp. 1425-1430.
8. Vincent FB, Northcott M, Hoi A, Mackay F, Morand EF. Clinical associations of serum interleukin-17 in systemic lupus erythematosus. *Arthritis Research & Therapy*, 15 (4), p. 97.
9. Vincent FB, Morand EF, Schneider P, Mackay F. The BAFF/APRIL system in SLE pathogenesis. *Nature Reviews Rheumatology* 2014 (accepted for publication).
10. Yap KS, Hoi A, Morand EF. Association of low vitamin D with high disease activity in an Australian SLE cohort. (in preparation)
11. Morand, EF Connelly, K; Hoi, AY. A polymorphism in the MIF gene is associated with cardiovascular morbidity in systemic lupus erythematosus - a pilot study. *Arthritis and Rheumatism*, 65: S1164-S1164.
12. Morand, EF Connelly, K; Hoi, AY. Serum concentrations of type I interferon-regulated chemokines are associated with disease activity in systemic lupus erythematosus. *Arthritis and Rheumatism*, 65: S275-S276.

### How we can help

Call our MSK Help Line and speak to our nurses. Phone 1800 263 265 or email [helpline@msk.org.au](mailto:helpline@msk.org.au).

We can help you find out more about:

- lupus and musculoskeletal conditions
- ways to live well with these conditions
- managing your pain
- upcoming webinars, seminars and other events.

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