

# What is the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS)?

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The Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS) is a group of investigators from across Canada who come together to do lupus research. Not all members participate in every project, and projects include collaborations with international researchers or other investigators outside the network.

The core of CaNIOS is our National Lupus Registry. With generous support from Lupus Canada we have developed a sophisticated, user friendly web-based platform, to replace the earlier 1000 Faces platform. As of December 2018, the registry included 650 lupus patients, and is growing rapidly. More than one quarter of these patients are newly diagnosed patients; these afford us the best opportunity for long-term follow-up with high quality data. We have also been working with an analyst to amalgamate the data from the previous registry with the new CaNIOS registry. This will increase the number of patients in the registry to more than 2,000 with exciting new possibilities for answering research questions. We review summary data at the annual investigators meeting, which allows us to examine trends in lupus manifestations, demographics and disease activity, and generates new research questions.

We recently published a paper outlining longitudinal disease activity in our CaNIOS lupus patients (“Persistent Disease Activity Remains a Burden for Patients with Systemic Lupus Erythematosus; *Journal of Rheumatology* 2018”). In this paper we showed that even after many years of disease, 35% of lupus patients still had active lupus, and a very high proportion of patients were taking glucocorticoids at significant doses to maintain disease control. This highlights the ongoing burden of lupus and the need for better treatment.

CaNIOS members are part of the MyLupusGuide, led by Dr. Paul Fortin, a project developed to provide up-to-date information and access to appropriate resources for persons with lupus and their healthcare providers. CaNIOS sites were and are involved in the development and testing of the application, and will be part of the disseminating process as well. It is funded by the Canadian Institutes of Health Research (CIHR) with support from Lupus Canada.



This project demonstrated the ability to reach many patients through CaNIOS; more than 1,500 patients were approached through CaNIOS investigators to participate in various stages of the project. This project is set to launch at the Lupus Canada Gala in May 2019 in Toronto.

CaNIOS sites are participating in Dr. Ann Clarke's economic analyses of the cost of systemic lupus erythematosus (SLE). This project is a large international collaboration to examine the cost of lost productivity in lupus patients. Dr. Clarke's healthcare utilization questionnaire is now also included in the CaNIOS registry.

The CaNIOS registry data, both the old and the new data sets, are being used to better understand the risk of eye toxicity associated with hydroxychloroquine, and understand the risks of lupus flare if hydroxychloroquine is stopped. This information will then be linked to an ongoing project to better understand patient preferences in decision-making with respect to hydroxychloroquine. This project is led by Drs. Sacha Bernatsky and Glen Hazelwood, and is funded by the CIHR.

In summary, we have lots on the go, and welcome new members and new sites!

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