



Maintaining CaNIOS' Strength, Sustainability and Success Through SARD Research Alliance (SRA)

"We can rejoice from the many successes we have experienced again this year", said Paul R. Fortin, the current Chair of CaNIOS. "Yet our measure of success will be if CaNIOS can renew itself." This was the message of renewal and rejuvenation that highlighted this year's 6th CaNIOS Principal Investigator's meeting in May in Winnipeg. Among several issues discussed by lupus researchers and their research assistants and coordinators during the meeting, the realization of the Systemic Autoimmune Rheumatic Disease (SARD) Research Alliance (SRA) was foremost in the future directions of the network. SRA represents a vision that is aimed toward the collaborative partnerships of several systemic rheumatic disease organizations. The basis whether this young yet unfunded alliance becomes successful is also dependent on whether CaNIOS remains strong, sustainable, and successful; and whether its sister founding member, the Canadian Scleroderma Research Group (CSRG) continues its unprecedented funding growth.

Two observers during the Winnipeg meeting on behalf of Lupus Canada, Debbie Dohan and Shari Kennedy, were fortunate to observe this year's interactive discussion and brainstorming among members on key issues such as infrastructure and research funding supports. Both witnessed the important milestones reported for two CaNIOS-led studies: the Genetic and Environmental Factors in SLE (GenES) and 1,000 Canadian Faces of Lupus. Both projects which are funded by the Canadian Institutes of Health Research (CIHR) are up for renewal this year, as did in a challenging way, the Health Improvement & Prevention Program (HIPP) last year. Notably, the Health Improvement and Prevention Program (HIPP) funding continues for 4 more years, and despite a 6-month funding interruption for which Lupus Canada and its provincial organizations pooled resources to keep the study afloat, HIPP continues recruitment in Toronto and Montreal, with the addition of London as a new site this summer. The renewed HIPP funding will allow CaNIOS to complete this randomized clinical trial and to obtain a definitive answer as to whether the HIPP intervention can improve the quality of life of those with lupus while decreasing their risk of serious complications such as cardiovascular disease or osteoporosis. Wendy Singer, a HIPP graduate, presented to the audience of the Lupus Canada Patient Symposium in Winnipeg a powerful testimonial. She described the empowerment she obtained during her HIPP participation. The knowledge she learned, the emotional and physical strength she gained, and the pro-active attitude empowered upon her by the study, helped her recover in a bout of lupus flare a year earlier.

Significantly, a spin off of the HIPP study, the Lupus Health Passport, has been generating interest from lupus patient associations south of the border such as the Lupus Foundation of America and Rheuminations, and from pharmaceutical companies who are interested in using the passport for baseline studies in their lupus clinical trials. Validation of an American version is thus forthcoming, and a French-Canadian version is currently being produced for use in French-speaking regions of Canada. CaNIOS owns the copyright to the passport and we hope that, as part of CaNIOS intellectual property, the passport will become synonymous to our brand. Simultaneously, discussions on how to transform the paper version into an electronic format have been ongoing for months, albeit sluggish due to lack of funding and sponsor. Three formats are being considered: a web-based portal supported and based on an institution's informatics platform, a web-based

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format designed to be hosted by a secure site outside of a hospital's informatics system, and an electronic format where patients can download the supporting program from a remote site to their personal computer, fill out the e-passport and/or carry their e-passport on a memory flash drive for update with a nurse practitioner. Whatever format it will be, the e-passport represents a tool aimed at empowering lupus patients with knowledge of their own condition and making them pro-active in up-to-date record keeping of their own personal health information.

Three important discoveries highlight CaNIOS research this year. First, the GenES study focusing on the analysis of autoantibodies from serum samples of parents and siblings of lupus patients, found an increased frequency of anti-nuclear antibodies (ANA) in lupus patients and their family members than expected when compared to population controls. Furthermore, GenES found that family members, as in lupus patients, have a significant decrease in the proportion of natural killer (NKT) cells (a type of white blood cell) which correlates with the presence of a positive ANA. This finding has now been submitted for peer review in a reputable scientific journal. Second, a budding rheumatologist working with the Lupus Nephritis New Emerging Team (LuNNET), Dr. Carolina Landolt Marticorena, reported in the recent Canadian Rheumatology Association (CRA) Meeting in Lake Louise, Alberta that increase in sustained T cell (a type of antibody-producing white blood cell) activation promotes disease activity in lupus. And lastly, data emerging from the 1000 Faces of Lupus Study which were also presented during the CRA meeting showed that aboriginal Canadian lupus patients appear to accumulate the most damage compared to Caucasian Canadian, Asian Canadian, and African Canadian patients. It is postulated that this may be due to socio-demographic and behavioral factors rather than to greater lupus activity or severity. The study suggests that aggressive risk management reduction and education may be of benefit in reducing damage accumulation. All these research findings from CaNIOS studies underscore the importance of the collaboration between researchers and patients in making headway toward a better understanding of their disease.

All research achievements mentioned came along with the struggle to maintain CaNIOS infrastructure. More stable infrastructure funds are needed to cover core CaNIOS National Office personnel such as the positions of the National Scientific and Development Coordinator, Administrative Coordinator, CaNIOS Database Manager/Administrator and CaNIOS Laboratory Technician. A solution to this perennial problem was articulated at the Winnipeg meeting by the CaNIOS Chair through his vision of the SRA. It will mean that CaNIOS needs to partner, initiate the creation, and growth of other systemic autoimmune rheumatic disease groups such as Scleroderma, Vasculitis, Sjögren's Disease, and Poly/Dermato-myositis. "By sharing the same infrastructure we can simultaneously advance research in these systemic rheumatic diseases," concluded Dr Fortin. A united, yet independent existence of these disease groups through a SRA virtual centre should not remain a dream for so long. As long as there are movers with great visions like the CaNIOS Chair.

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