



CaNIOS

IN TOUCH

CaNIOS Research Participants Newsletter

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Healthcare Cost and Loss of Productivity



Lupus researchers recruited 141 patients with (LN) and without lupus nephritis (LNN) and classified them as active (ALN and ALNN) and inactive disease (LIN and ILNN). Then patients reported on their visits to healthcare professionals, the use of health care services and their work productivity in the 4 weeks preceding enrollment.

Results have shown that out of the 141 recruited SLE patients, 79 had LN. The LN group was more likely to visit rheumatologists and nephrologists, undergo diagnostic tests, and had higher costs for medications than patients without LN. The annual healthcare cost averaged \$CAN 12,597 ± 9946 for patients with LN and \$10,585 ± 13,149 for LNN patients, a difference of \$2012 (95% CI -\$2075, \$6100). Patients with ALN had more diagnostic tests and surgical procedures, contributing to a significantly higher annual direct cost (\$14,224 ± 10,265) compared to patients with ILN (\$9142 ± 8419) with a difference of \$5082 (95% CI \$591, \$9573). The healthcare cost was not different between patients with ALNN and patients with ILNN. Among the LN and LNN patients, less than 50% were employed and on average missed 6.5-9 days of work per month. The loss of productivity was significantly higher for caregivers of patients with LN than caregivers of patients who were LNN. In summary, healthcare cost and loss of productivity were higher in patients with LN especially in those with active disease. (Selected from Aghdassi E, Zhang W, St-Pierre Y, Clarke AE, Morrison S, Peeva V, Landolt-Marticorena C, Su J, Reich H, Scholey J, Herzenberg A, Pope JE, Peschken C; LuNNET CaNIOS Investigators, Wither JE, Fortin PR. *Healthcare cost and loss of productivity in a Canadian population of patients with and without lupus nephritis.* J Rheumatol. 2011 Apr;38(4):658-66.)

SPECIAL POINTS OF INTEREST:

- Healthcare Cost and Loss of Productivity
- 2011 Arthritis Scientific Conference
- Updates on CaNIOS Studies
- Changes to CaNIOS Centre 17: University Health Network CPSRD
- 1st New Treatment for Lupus
- Young Adult, Health & Employment Study

Update on 2011 Canadian Arthritis Network Annual Scientific Conference Quebec City, October 25-30, 2011

For the first time ever, the Canadian Arthritis Network (CAN), the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS), the Canadian Association of Pediatric Rheumatology Investigators (CAPRI) and the Canadian Scleroderma Research Group (CSRG) partnered together to host an arthritis conference. From October 25-30, approximately 400 members, trainees, industry representatives and stakeholders met and discussed program issues and their research.

Over 100 students, staffs and researchers attended the two-days Training Day and Interactive Event with an introduction to research programs and overview of opportunities for graduate students, clinical and research trainees. This was followed by short presentations from several clinical and research members on multi-disciplinary topics. The Training Days ended on a high note with the Mentorship Mocktails which gave enthusiastic students the opportunity to network and approach faculty members about potential collaboration opportunities.

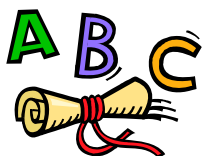
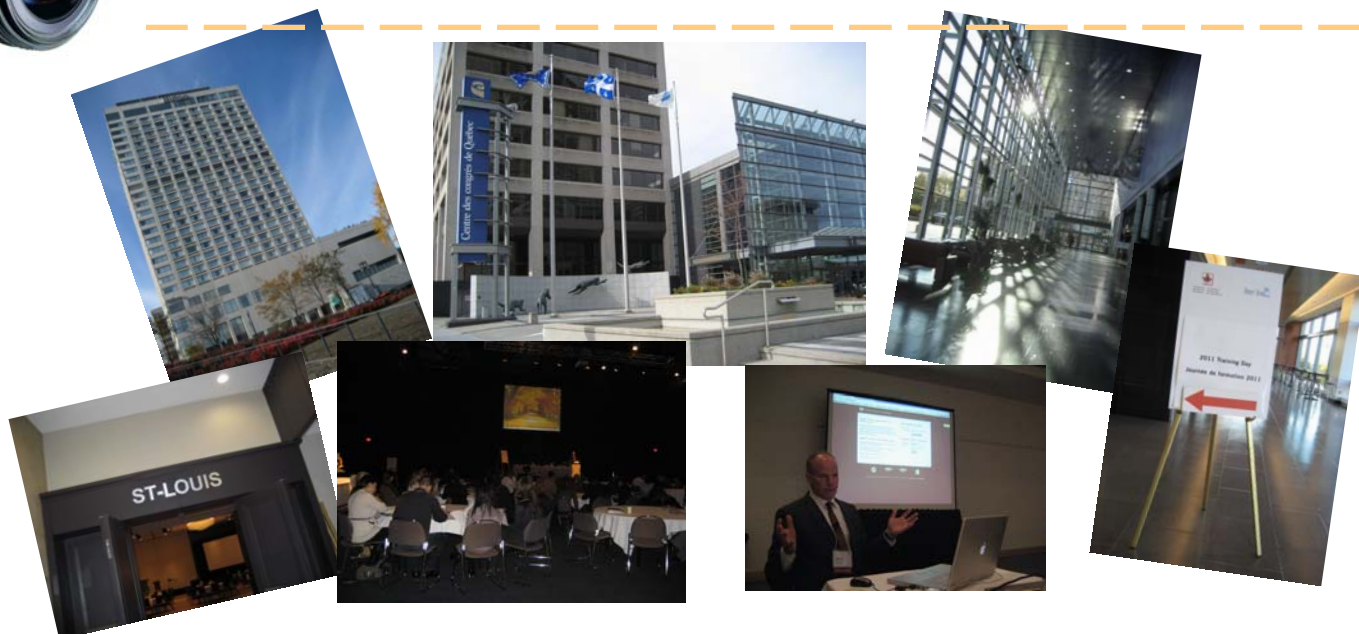
The first CSRG/CaNIOS joint meeting happened on the last day. Several guest speakers presented their area of interests, and some of the guests included Mr. Murray Rochon from the Jack Digital Productions Inc who shared the concept of the 'Navigator' with Ms. Louise Bergeron as a patient advocate and with Dr. Paul R. Fortin, CaNIOS President. Dr. Brett Thombs, PhD in Clinical Psychology and Psychometrics presented the topic on 'The Scleroderma Patient-centered Intervention Network (SPIN)'. Furthermore, Dr. Eric Boilard, PhD in Microbiology-Immunology from the Centre de Recherche en Rhumatologie et Immunologie, CRCHUQ, Universite Laval, Quebec, QC presented the topic on 'Platelet microparticles contribute to inflammatory arthritis and are associated with immune-complexes'.

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Photos Taken from the 2011 Canadian Arthritis Network Annual Scientific Conference



Research Update: Request for Applications The GSK-CaNIOS-CRA-TAS Lupus Fellowship

In partnership with GlaxoSmithKline Inc. (GSK), CaNIOS and The Canadian Rheumatology Association (CRA), The Arthritis Society is pleased to announce the inaugural competition for the GSK-CaNIOS-CRA-TAS fellowship for the 2012-13 granting year. This opportunity is a two-year funding (2012-13 and 2013-14) to allow post-graduate to increase research expertise in lupus in Canada. The research award will be administered under auspices of the CaNIOS, the CRA and TAS. The second year of the funding will be based upon successful review of progress of the first year of the fellowship. To learn more information, please visit:

http://www.arthritis.ca/look%20at%20research/calls_for_applications/gsk/default.asp?s=1

CaNIOS



New Faces at the Centre de Recherche du Centre Hospitalier Universitaire de Québec –CHUL and Changes to CaNIOS Centre 17, University Health Network CPSRD

This year brings some significant staff changes at the Centre 17 University Health Network CPSRD. While program goes on as before, Dr. Paul R. Fortin moved from the University Health Network in Toronto to the Centre de Recherche du Centre Hospitalier *Universitaire de Québec* (CRCHUQ) in Quebec in summer 2011. Dr. Ellie Aghdassi, CaNIOS Scientific Associate accepted a position at the Toronto Dementia Research Alliance. Mr. Jiandong Su, CaNIOS database administrator also moved on with another data administrator position at the Institute for Clinical Evaluative Sciences (ICES). Ms. Stacey Morrison will remain as a Research Analyst for some of the studies, but will only work part-time starting September 2011. Ms. Cathy Chau, CaNIOS Research and Business Development Administrator will continue to work for CaNIOS on a part-time basis.

In the mean time, I am delighted to announce that Ms. Davy Eng and Ms. Julie Parrot will be joining the CaNIOS family in Quebec. Davy will take on the position as a Scientific and Development Coordinator to help coordinate CaNIOS research activities and Ms. Julie Parrot will take on the CaNIOS administrative matters. Please join me in welcoming Davy and Julie.



Update on the e-LHP

Electronic Lupus Health Passport (e-LHP)

The **Lupus Health Passport (LHP)** - a spiral bound, pocket-sized booklet summarizing patient's disease profile, blood test results, past and current medications, their treatment plan, prevention strategies for heart disease and osteoporosis, annual examinations and contact information has now been transformed into a web-based platform (e-LHP). CaNIOS in collaboration with the Jack Digital Production Inc. is finalizing and validating the Web version of the passport. The validation process began earlier this year in Toronto, and to date 10 patients and 6 health care providers from Toronto have tested the e-LHP. CaNIOS is waiting to hear back from other validation participants located in 5 other CaNIOS centers. We foresee the e-LHP will be ready for patients to use by the middle of 2012.

Update on the Lupus Interactive Navigator (LIN)

Empowering Patients as Active Partners in Their Care: Lupus Interactive Navigator (LIN)

While lupus is a disease with no cure and chronic fatigue and inflammation and may lead to early disability, CaNIOS with the support of the Canadian Institute of Health Research (CIHR) and the Jack Digital Production Inc. (JDP Inc.) are collaborating to develop the Lupus Interactive Navigator — the knowledge transfer tool. LIN will use an approach based on the person-center model which integrates psychosocial elements of education and self-management focusing on wellness as part of standard care. In order to identify care gaps in lupus and build the web-based LIN with JDP Inc., consultation with various stakeholders and consumers will take place, Working with patient organizations such as Lupus Canada, the Canadian Rheumatology Association and Consumer Groups will allow us to develop guidelines for broader use of the LIN. The ultimate goal is that LIN will improve patients' quality of life and have it adopt as a standard of care for lupus patients.

To date, CaNIOS is working hard to develop survey questionnaires for the needs assessment that will be circulated to the focus groups. If resources allow, CaNIOS will also survey policy makers and industry partners. Finally, the LIN will be developed to suit needs of patients and clinicians.

Health Canada Approves First New Treatment for Lupus in Almost 50 Years



On July 12, 2011, Health Canada has approved BENLYSTA™ (belimumab) as the first drug specific for the treatment of systemic lupus erythematosus. According to GlaxoSmithKline Inc. (GSK) and Human Genome Sciences (HGS) who developed BENLYSTA™, the drug is expected to be available to patients in Canada starting September 2011. To learn more about the new drug, please contact your doctor.

YhES!

Young Adult, Health & Employment Study

YHES! The Young Adult, Health & Employment Study is an online survey examining the experience of finding and maintaining employment among Canadian young adults living with lupus. Participants also have the choice of completing the questionnaire over the phone or by paper. Young adults between the ages 18 to 30 years living with lupus who are at least one year post-diagnosis are invited to participate in the study. Participants must live in Canada and can either be currently employed, not employed or may have never held a job. Involvement in the study will include one online questionnaire that takes about 30 minutes to complete. The online questionnaire will ask about the types of work activities and conditions that may create problems for people living with chronic diseases, perceptions of work and the changes to work that might help young people remain employed. In addition, questions will ask about the participant's life and health. **For more information on how to participate, please contact:** Arif Jetha Toll Free at 1-855-469-4540 OR by, email at yhes@uhnresearch.ca And Visit our website at www.yhes.ca

CaNIOS Research Study Enrollments

1000 Faces of Lupus Enrolled = 2403
01 (MGH, Montréal)
04 (Maisonneuve)
06 (QEII, Halifax)
07 (OGH, Ottawa)
08 (SJHSC, London)
10 (WHSC, Winnipeg)
15 (ARC, Vancouver)
17 (TWH, Toronto)
19 (Non-CPS, Toronto)
26 (Lethbridge Regional)
29 (Edmonton)
33 (Jewish General, Montreal)

HIPP = Closed
GenES Recruitment = Closed
ThromboFIL Recruitment = Closed
LuNNET Cohort 2 & 3 Enrolled = 255
Centre 01 MGH
Centre 17 TWH-CPS
Centre 19 Winnipeg
Centre 8 London

About CaNIOS

CaNIOS is a unique collaboration that brings together widespread scientific and clinical expertise in a coordinated and collaborative spirit which allows Canadian researchers to address several questions important to patients with lupus and their families. Founded in 1995 when the current chair, Dr. Paul R. Fortin was at the Montreal General Hospital, CaNIOS Coordinating Centre moved to Toronto Western Hospital in 2000. Dr. Fortin has again moved to the Université Laval in Fall 2011. CaNIOS maintains a database of lupus patients through its National Lupus Registry which combines data from different centres through a standardized data collection system. CaNIOS has been supported solely by funding from individual operating grants from governmental agencies and non-for-profit organizations and foundations. **For more information, please visit www.CaNIOS.ca**



Upcoming Event ... **WALK for lupus**

Lupus Canada in partnership with its Provincial Member Organizations and Divisions are working together to improve the lives of the tens of thousands of Canadians living with lupus. The annual fundraising and public awareness event ‘Walk for Lupus’ usually take place in May and it attracts clinicians, researchers, trainees, patients and their family members to participate to help raise funds to conquer lupus. In 2012 the Walk for Lupus will be celebrating its 11th year and we invite you, your family and friends to join us to mark this our most successful year. Should you have any questions or require additional information, please contact your local Walk Coordinator at your Provincial Member Organization/ Division or visit the following Website: <http://www.walkforlupus.ca/>

CaNIOS publishes **In Touch** in January and July. Electronic copy can be downloaded by visiting the CaNIOS website. If you have any comments, wish to advise of a change of e-mail address, or be added or removed from the mailing list, please contact **In Touch**. **The following are contributors to this issue:** Dr. Paul R. Fortin, Dr. Ellie Aghdassi, Ms. Cathy Chau, Ms. Davy Eng, Ms. Stacey Morrison, Ms. Julie Parrot, and Mr. Jiandong Su.