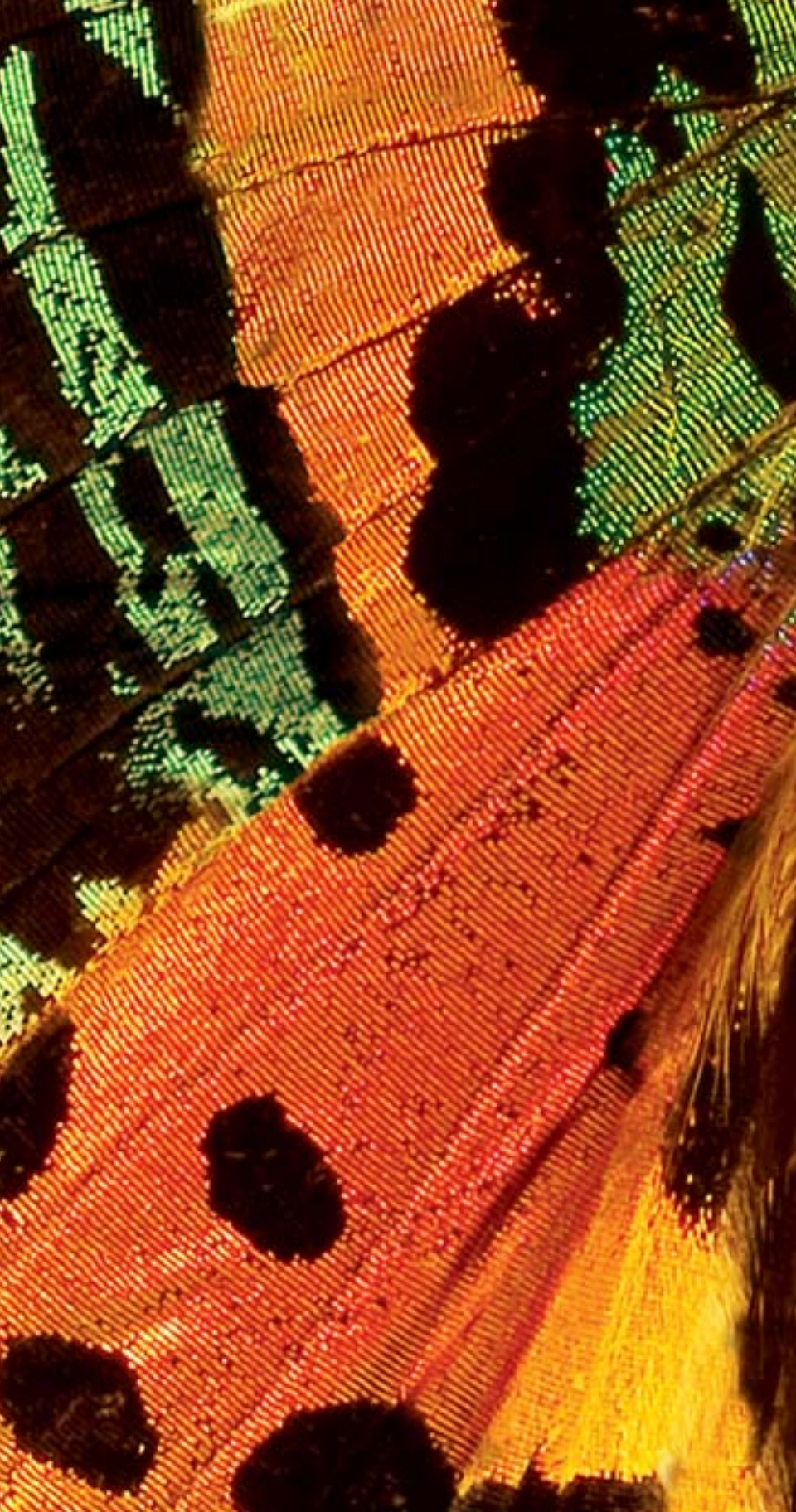




CANADIAN NETWORK FOR IMPROVED OUTCOMES
IN SYSTEMIC LUPUS ERYTHEMATOSUS

CaNIOS

www.CaNIOS.ca



A GROUP
OF CANADIAN
INVESTIGATORS
COMING TOGETHER
TO IMPROVE
THE OUTCOME
OF LUPUS
PATIENTS
ACROSS
OUR COUNTRY
THROUGH
COLLABORATIVE
RESEARCH.

MISSION



GOALS

- 1 To facilitate the care of Canadians with lupus.
- 2 To improve the outcomes of Canadians with lupus.
- 3 To describe the population of lupus patients in Canada.
- 4 To facilitate research in lupus and related autoimmune diseases.
- 5 To provide a large patient base to address clinically important issues through research.
- 6 To take advantage of the unique features in the Canadian lupus population.
- 7 To look at sub-groups of the Canadian lupus population: the pediatric lupus patients, minorities, and men.
- 8 To contribute to the global and international effort on lupus research through the uniqueness of the Canadian lupus population.
- 9 To provide mentorship to young investigators and trainees who are interested in developing a career in lupus research.

CaNIOS was created in 1995 with the specific goal of running a multi-centre, randomized, controlled Study of Methotrexate in Lupus Erythematosus (SMILE). The SMILE study was funded by The Arthritis Society of Canada. Because of the low prevalence of lupus such a randomized controlled trial could not be conducted at a single centre. In order to obtain the required sample size, a Canada-wide collaboration was developed through the leadership of Dr. Paul R. Fortin.

BACKGROUND HISTORY

CaNIOS brought together many lupus experts who, despite their limited individual lupus cohorts, were able to pool information for the completion of the SMILE study. Since its inception, CaNIOS has had up to a total of 57 clinicians affiliated with 28 Canadian academic-based rheumatic disease units and community rheumatology clinics, and hundreds of patients participating simultaneously in the research effort. In addition to their work on SMILE, the CaNIOS investigators and their cohorts have proved a very useful tool for the conduct of other lupus research in the country. Two subsequent studies were funded relatively quickly after the creation of CaNIOS. They include a large randomized, controlled trial of a group support therapy in lupus erythematosus, and a study of the prevalence of malignancy in lupus. Neither of these studies could have been performed without CaNIOS.

CaNIOS has received 13 peer-reviewed grants to date. Its members have published 10 journal articles and 21 abstracts. CaNIOS members have also been prominent leaders in the revision of the patient information book "Lupus: The Disease with a Thousand Faces".

CaNIOS maintains a database of lupus patients through its National Registry. The idea is to combine data from different centers through a standardized data collection system in order to describe SLE in Canadians, increase the power of medical research, and exchange valuable clinical information between doctors and researchers.

The **Lupus Health Passport** is a recent project developed to serve as a tool to administer and monitor an ongoing experimental program on health improvement and prevention in SLE. This will directly benefit persons living with lupus once validation studies are completed.

CaNIOS exists through limited peer-reviewed funding. Until now, CaNIOS has been supported solely by funding from individual operating grants from governmental agencies and non-for-profit organizations. Since September 2001, a donor, in partnership with Lupus Canada and the Arthritis and Autoimmune Research Centre (AARC) at University Health Network have supported CaNIOS infrastructure. Since 2004, the Lupus Clinical Trial Consortium have provided salary supports for a CaNIOS Director and Coordinator. These have allowed CaNIOS to develop a database platform and to establish an efficient lupus clinical trial network in Canada. CaNIOS is aiming to expand its infrastructure, with investigator-driven projects in development. Peer-reviewed grants cover the direct cost of performing investigator-driven research studies but the overall cost of maintaining an infrastructure such as that required by CaNIOS exceeds what can be obtained through peer-reviewed funding.

EXECUTIVE BOARD

The Executive Board consists of a chair, vice chair, secretary/treasurer, and an executive member. The executive meet regularly once a month by teleconference.

Chair - Dr. Paul R. Fortin (Toronto) has been in this position since the creation of CaNIOS in 1995.

Vice-Chair - Dr. Janet Pope (London) has been in this position since 2001.

Secretary-Treasurer - Dr. C. Doug Smith (Ottawa) has been in this position since 2001.

Executive Member - Dr. Christine Peschken (Winnipeg) joined the executive in 2004.

SUB COMMITTEES

The original subcommittees were the Scientific Committee, Membership Committee, Fund-Raising and Finance Committee, Authorship Committee and Telematics and Database Infrastructure Committee. The Fundraising and Finance Committee and the Authorship Committee have been closed and their responsibilities now rest with the Executive Board. Recent changes to the committees include the addition of the Data Access and Data Standards Committees in 2005 which now take the place of the former Telematics committee. Also in 2005, the Privacy & Compliance Committee was developed. These committees meet via conference calls once every 3-4 months as workload dictates.

CaNIOS functions through conference calls and through an annual scientific meeting, which is planned to happen at the same time as its business meeting and at the same time and location of the Lupus Canada General Assembly and Annual Patient Symposium.

CaNIOS Chair

Paul R. Fortin, MD, MPH, FRCPC
Associate Professor of Medicine,
University of Toronto
UHN - Toronto Western Hospital
Director of Clinical Research,
Arthritis Centre of Excellence

CaNIOS Vice-Chair

Janet E. Pope, MD, FRCPC
Associate Professor,
Medicine & Epidemiology & Biostatistics,
University of Western Ontario
St. Joseph's Health Care - London

CaNIOS Secretary/Treasurer

C. Douglas Smith, MD, FRCPC
Associate Professor,
University of Ottawa
The Ottawa Hospital, Riverside

CaNIOS Executive Member

Christine A. Peschken, MD, FRCPC
Assistant Professor,
University of Manitoba
Arthritis Centre

CaNIOS National Scientific & Development Coordinator

Jaime O. Claudio, Ph.D.
UHN - Toronto Western Hospital

CaNIOS Business Administrator

Luciana Brown, B.A.S.
UHN - Toronto Western Hospital

RELEVANCE OF FUTURE CaNIOS RESEARCH TO PATIENTS

CaNIOS is a unique collaboration that allows Canadian researchers to address several questions important to persons with lupus and to their families. Current examples of questions that are on the “to do list” of CaNIOS investigators include the following: Why are autoimmune diseases more frequent in some families? What are the roles of gender, the environment and genetic factors in the development of lupus? Why are cardiovascular diseases more frequent among lupus patients? Can we prevent heart attacks and strokes in lupus patients? How can we better understand neuropsychiatric lupus manifestations? What happens to children with lupus? Why are the people of some Canadian First Nations more prone to lupus? Furthermore, CaNIOS can bring to Canadian patients new experimental treatments developed in other countries, and can study their risks and benefits in a Canadian environment.

However, these goals can only be achieved if lupus patients provide strong support to research initiatives across Canada, by participating in CaNIOS research projects.

SUMMARY

CaNIOS is a unique tool for the Canadian lupus community, since it brings together widespread scientific and clinical expertise in a coordinated and collaborative spirit for the benefit of all persons with lupus.

CANIOS CENTRES

The Canadian Network for
Improved Outcomes in SLE



BRITISH COLUMBIA

Vancouver
Prince George

ALBERTA

Edmonton
Calgary
Lethbridge

SASKATCHEWAN

Saskatoon

MANITOBA

Winnipeg

ONTARIO

London
Hamilton
Toronto
Kingston
Ottawa

QUÉBEC

Montreal
Sherbrooke
Quebec City

NEW BRUNSWICK

Fredericton
Moncton

NOVA SCOTIA

Halifax

NEWFOUNDLAND

St. John's

SELECTED PUBLICATIONS

PUBLISHED

- 1 Dobkin PL, Da Costa D, Fortin PR, Edworthy S, Barr S, Esdaile JM, Senecal JL, Goulet JR, Choquette D, Rich E, Beaulieu A, Cividino A, Ensworth S, Smith D, Zummer M, Gladman DD, Clarke AE. Living with lupus: A prospective pan-Canadian study. *Journal of Rheumatology*. 2001;28(11):2442-2448. (Coll)
- 2 Dobkin PL, Da Costa D, Joseph L, Fortin PR, Edworthy S, Barr S, Ensworth S, Esdaile JM, Beaulieu A, Zummer M, Sénécal JL, Goulet JR, Choquette D, Rich E, Smith D, Cividino A, Gladman D, St-Pierre Y, Clarke AE. Counterbalancing patient demands with evidence: Results from a Pan-Canadian randomized clinical trial of brief supportive-expressive group psychotherapy for women with systemic lupus erythematosus. *Annals of Behavioural Medicine*. 2002;24(2):88-99. (Coll)
- 3 Chang E, Abrahamowicz M, Ferland D, Fortin PR. Comparison of the responsiveness of lupus disease activity measures to changes in systemic lupus erythematosus activity relevant to patients and physicians. *Journal of Clinical Epidemiology*. 2002;55(5):488-497. (SA)
- 4 Chang ER, Abrahamowicz M, Ferland D, Fortin PR, for CaNIOS investigators. Organ manifestations influence differently the responsiveness of two lupus disease activity measures, according to patients' or physicians' evaluations of recent lupus activity. *Journal of Rheumatology*. 2002;29(11):2350-2358. (Coll)
- 5 Edworthy SM, Dobkin PL, Clarke AE, Da Costa D, Dritsa M, Fortin PR, Barr S, Ensworth S, Esdaile JM, Beaulieu A, Zummer M, Sénécal JL, Goulet JR, Choquette D, Rich E, Smith D, Cividino A, Gladman DD, Devins GM. Group psychotherapy reduces illness intrusiveness in systemic lupus erythematosus. *Journal of Rheumatology*. 2003;30(5):1011-1016. (Coll)
- 6 Clarke AE, Petri M, Manzi S, Isenberg DA, Gordon C, Senecal J-L, Penrod J, Joseph L, St. Pierre Y, Fortin PR, Sutcliffe N, Goulet J-R, Choquette D, Grodzicky T, Esdaile J. The systemic lupus erythematosus tri-nation study: Absence of a link between health resource use and health outcome. *Rheumatology*. 2004;43(8):1016-1024. (Coll)
- 7 Bernatsky S, Ramsey-Goldman R, Boivin J-F, Joseph L, Rajan R, Zoma A, Manzi S, Ginzler E, Urowitz M, Gladman D, Fortin PR, Petri M, Edworthy E, Barr S, Gordon C, Bae S-C, Sibley J, Isenberg D, Rahman A, Aranow C, Dooley M-A, Steinsson K, Nived O, Sturfelt G, Alarcon G, Senecal J-L, Zummer M, Hanly J, Ensworth S, Pope J, El-Gabalawy H, McCarthy T, St. Pierre Y, Clarke A. An international cohort study of cancer in systemic lupus erythematosus (SLE). *Arthritis and Rheumatism*. 2005;52(5):1481-90. (coll)
- 8 Chagnon P, Schneider R, Herbert J, Fortin PR, Provost S, Bellisle C, Gingras M, Bolduc V, Perreault C, Silverman E, Busque L. Identification and characterization of an Xp22.33 ; Yp11.2 translocation causing a triplication of several genes of the PAR1 region in an XX male patient with severe systemic lupus erythematosus. (conditional acceptance to Arthritis & Rheumatism- July 2005) (coll).

- 9 Bernatsky S, Boivin J-F, Joseph L, Manzi S, Ginzler E, Urowitz M, Gladman DD, Fortin PR, Gordon C, Barr S, Edworthy S, Bae S-C, Petri M, Sibley J, Isenberg D, Rahman A, Steinsson K, Aranow C, Dooley MA, Alarcón G, Hanly J, Sturfelt C, Nived O, Pope J, Ensworth S, Rajan R, El-Gabalawy H, McCarthy T, St. Pierre Y, Clarke A, Ramsey-Goldman R. Race/Ethnicity and cancer occurrence in systemic lupus erythematosus. *Arthritis & Rheumatism*. 2005;53(5):781-784. (coll)
- 10 Bernatsky S, Ramsey-Goldman R, Rajan R, Boivin J-F, Joseph L, Lachance S, Cournoyer D, Zoma A, Manzi S, Ginzler E, Urowitz M, Gladman DD, Fortin PR, Edworthy S, Barr S, Gordon C, Bae S-C, Steinsson K, Sturfelt C, St. Pierre Y, Clarke A. Non-Hodgkin's lymphoma in systemic lupus erythematosus. *Ann Rheum. Dis*. 2005;64:1507-1509. (coll)
- 4 Dobkin PL, Da Costa D, Dritsa M, Fortin PR, Sénécal JL, Goulet JR, Choquette D, Esdaile JM, Beaulieu A, Cividino A, Edworthy S, Barr S, Ensworth S, Gladman D, Smith D, Zimmer M, Rich E, Clarke AE. Quality of life in SLE during active and inactive disease states: Differential contributors to mental and physical health. *American Psychosomatic Society*, Vancouver, March 1, 1999. (Coll)
- 5 Fortin PR, Abrahamowicz M, Ferland D, SMILE Coinvestigators. Lupus disease activity measures are responsive to change in the study of methotrexate in lupus erythematosus (SMILE). *Arthritis & Rheumatism* 1999;42(9 suppl):S99. (PA)
- 6 Fortin PR, Abrahamowicz M, Ferland D. Lupus disease activity measures are responsive to change in the study of methotrexate in lupus erythematosus (SMILE). *Journal of Rheumatology* 2000;27:1813. (PA)

BOOKS

Lupus: the disease with a thousand faces. Your Personal Health Series. Eds. Jean-Luc Sénécal and Sasha Bernatsky. Key Porter Books. 2004. (Coll).

ABSTRACTS

- 1 Dobkin PL, Clarke AE, Fortin PR, Joseph L, Danoff DS. Psychosocial contributors to mental and physical health in patients with systemic lupus erythematosus. *Psychosomatic Medicine* 1997;59:77-108(p.84-85). (Coll)
- 2 Da Costa D, Pinar L, Dobkin PL, Clarke AE, Fortin PR, Danoff DS, Esdaile JM. A prospective study on the role of stress in functional disability among women with SLE. *Lupus* 1998;7(Suppl.):51. (Coll)
- 3 Da Costa D, Clarke AE, Dobkin PL, Sénécal JL, Goulet JR, Choquette D, Grodzicky T, Fortin PR, Danoff DS, Esdaile JM. Social support and health status influence satisfaction with medical care among patients with systemic lupus erythematosus. *Psychosomatic Medicine* 1998;60:130. (Coll)
- 7 Dobkin P, Clarke A, DaCosta D, & LEAP Group. Supportive-expressive group psychotherapy for women with SLE: A Pan-Canadian randomized clinical trial. *Journal of Psychosomatic Research* 2000;48:241. (Coll)
- 8 Clarke A, Dobkin P, Da Costa D, St. Pierre Y, Fortin PR, Edworthy S, Barr S, Ensworth S, Esdaile J, Beaulieu A, Sénécal JL, Rich E, Choquette D, Goulet JR, Smith D, Cividino A, Zimmer M, Gladman D. A randomized multi-site controlled trial of group psychotherapy for SLE. *Arthritis & Rheumatism* 2000;43(9 suppl):S149. (Coll)
- 9 Chang ER, Fortin PR, Ferland D, Abrahamowicz M. The effect of organ system items on the responsiveness of SLAM-R and SLEDAI to changes in disease activity relevant to physicians and patients. *Arthritis & Rheumatism* 2000;43(9 suppl):S148. (Coll)
- 10 Nashi E, Clarke A, Joseph L, Fortin PR. The incidence of cancer in patients with systemic lupus erythematosus. *Arthritis & Rheumatism* 2000;43(9 suppl):S165. (SA)

- 11 Chang E, Abrahamowicz M, Ferland D, Fortin PR. Overall and system-specific responsiveness of SLAM-R and SLEDAI to changes in disease activity relevant to physicians and patients. *Journal of Rheumatology* 2001;28(6):12. (PA)
- 12 Chang E, Abrahamowicz M, Ferland D, Fortin PR. Overall and system-specific responsiveness of SLAM-R and SLEDAI to changes in disease activity relevant to physicians and patients. *Lupus* 2001; 10(suppl); abstract #315, S109. (SA)
- 13 Fortin PR, Abrahamowicz M, Ferland D, Lacaille D, Smith CD, Zummer M, CaNIOS. Study of methotrexate in lupus erythematosus (SMILE): Significant decreased disease activity and steroid sparing effect in patients without damage. *Arthritis and Rheumatism* 2001;44(9 suppl):S2004. (SA)
- 14 Chang ER, Abrahamowicz M, Ferland D, Fortin PR. Subjective items contribute, independently of objective items, to the responsiveness of SLAM-R to patient- and physician-reported changes in SLE disease activity. *Arthritis and Rheumatism* 2001;44(9 suppl):S1160. (Coll)
- 15 Bernatsky S, Ramsey-Goldman R, Boivin JF, Joseph L, Rajan R, Zoma A, Manzi S, Urowitz M, Gladman D, Fortin PR, Gordon C, Bae SC, Sibley J, Edworthy S, Barr SG, Isenberg D, Rahman A, El-Gabalawy H, Senecal JL, Zummer M, Steinsson K, Hanly J, Pope J, Nived O, Clarke A. Cancer in Systemic Lupus Erythematosus (SLE): An International Multi-Centre Cohort Study. *Arthritis and Rheumatism* 2003;48(9 suppl):S696 (Coll)
- 16 Bernatsky S, Clarke A, Boivin JF, Joseph L, Rajan R, Manzi S, Urowitz M, Gladman D, Fortin PR, Gordon C, Bae SC, Sibley J, Edworthy S, Barr S, Isenberg D, Rahman A, El-Gabalawy H, McCarthy T, Hanly J, Pope J, Sturfelt G, Nived O, St. Pierre Y, Ramsey-Goldman R. Racial Factors Relating to Cancer Occurrence in Systemic Lupus (SLE). *Arthritis and Rheumatism* 2003;48(9 suppl):S696 (Coll)
- 17 Bernatsky S, Clarke AE, Rajan A, Boivin J-F, Joseph L, Lachance S, Cournoyer D, Zoma A, Manzi S, Ginzler E, Urowitz M, Gladman D, Fortin PR, Edworthy S, Barr S, Gordon C, Sibley Nived O, Sturfelt G, St. Pierre Y, Ramsey-Goldman R, Non-Hodgkin's lymphoma in systemic lupus erythematosus. *Arthritis and Rheumatism* 2004;50 (9 suppl)S691 (Coll).
- 18 Bernatsky S, Ramsey-Goldman R, Boivin J-F, Joseph L, Rajan R, Zoma A, Manzi S, Ginzler E, Urowitz M, Gladman D, Fortin PR, Petri M, Edworthy S, Gordon C, Bae S-C, Sibley J, Isenberg D, Aranow C, Dooley M-A, Steinsson K, Nived O, Sturfelt G, Alarcon G, Clarke AE. An international cohort study of cancer in systemic lupus erythematosus (SLE). *Arthritis and Rheumatism* 2004;50 (9 suppl)S592 (Coll)
- 19 Bernatsky S, Boivin J-F, Joseph L, Rajan R, St. Pierre Y, Ramsey-Goldman R, Clarke AE, Systemic Lupus International Collaborating Clinics (SLICC), Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS). Mortality in systemic lupus erythematosus: Risk according to cause, age, sex and lupus duration. *American College of Rheumatology, 2005*. San Diego, CA, November 2005.
- 20 Bernatsky S, Boivin J-F, Joseph L, Rajan R, St. Pierre Y, Ramsey-Goldman R, Clarke AE, Systemic Lupus International Collaborating Clinics (SLICC), Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS). The Influence Of Geographical And Racial/ethnic Factors On Mortality Risk In Systemic Lupus Erythematosus. *American College of Rheumatology, 2005*. San Diego, CA, November 2005.
- 21 Bernatsky S, Boivin J-F, Joseph L, Rajan R, St. Pierre Y, Ramsey-Goldman R, Clarke AE, Systemic Lupus International Collaborating Clinics (SLICC), Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS). Trends in relative mortality rates for systemic lupus erythematosus over calendar time. *American College of Rheumatology, 2005*. San Diego, CA, November 2005.

CONTACT INFORMATION

Web Site: www.CaNIOS.ca and www.CaNIOS.org

CaNIOS National Scientific & Development Coordinator

Jaime O. Claudio, Ph.D.

Tel: 416-603-5800 x3158

Fax: 416-603-6288

E-mail: jclaudio@uhnresearch.ca

Mailing Address

UHN – Toronto Western Hospital

399 Bathurst Street, MP 10-303

Toronto, Ontario M5T 2S8

CaNIOS Business Administrator

Luciana Brown, B.A.S.

Tel: 416-603-6267

Fax: 416-603-6288

E-mail: lucianab@uhnresearch.ca

Mailing Address

UHN – Toronto Western Hospital

399 Bathurst Street, MP 10-306

Toronto, Ontario M5T 2S8