

# CaNIOS Newsletter

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## Important Dates

**Feb 18-21, 2009** – CRA Scientific Programme, Kananaskis, Alberta

**April 2-3 2009** – CaNIOS Annual Meeting in Toronto

**April 4, 2009** – 8th Annual Patient Symposium

**May 9-10, 2009** – Walk-a-Block for Lupus 2009.

**June 26, 2009** - ACR Abstract deadline

**June 23-27, 2010** – International Lupus Congress, Vancouver, BC

## INSIDE:

Abstracts submitted	p2
Papers submitted	p2
Manuscripts in preparation	p2
Recruitments	p3



## Thank You Lupus Ontario

In the recent Dance For the Cure fundraising event held on January 24, 2009, CaNIOS member Dr. Murray Urowitz was awarded the Lupus Ontario **Hope Award** for outstanding leadership in improving the lives of people living with lupus. In acknowledging the award, Dr. Urowitz spoke about the highest degree of patient participation in research. He was referring to “patients being participants in lupus research, and funding research to find a cure for lupus.” The Dance for the

Cure Fundraising Gala has been raising funds for Lupus Ontario, the Pediatric Lupus Clinic at Sick Kids in Toronto (CaNIOS Centre 20), and the Arthritis and Autoimmune Research Foundation (AARCF) at University Health Network. The proceeds AARCF receives specifically support the Systemic Lupus International Collaborating Clinic (SLICC) and its registry, and the University of Toronto Lupus Clinic Registry (CaNIOS Centre 17) at Toronto Western Hospital. In the same event,

Julia Kane, President of Lupus Ontario, presented a \$20,000 donation to CaNIOS. Thank you Lupus Ontario for the ongoing partnership. This donation will secure the activities of the National Coordinating centre and allow for several studies to continue. CaNIOS is thankful for the support it has enjoyed from all of the Lupus organizations in Canada since 1995. CaNIOS has become an influential network that is poised to make significant contributions nationally and internationally.

## Pharma Support

With funding for infrastructure becoming scarce, the CaNIOS Coordinating Centre approached several pharmaceutical companies in the fall for unrestricted educational funds. The response has been encouraging. Very recently, UCB Pharma responded with a

generous donation of \$10,000 for this year, with potential support again next year, pending corporate approval. We are also following up discussions with Roche and Eli Lilly for unrestricted research partnership in regards to our PRECEDES grant applica-

tion from the Canadian Arthritis Network to fund SARD research. Roche has committed support for the 1st year of the grant, with pending commitment for the second year. We are still awaiting a response from Eli Lilly. We will keep you posted.

## In Touch/Contact

We have been receiving positive feedbacks on our In Touch/Contact. One subscriber wrote: “Nice job on the latest In Touch newsletter. I found it interesting, informative and humorous.” Another subscriber said: “Thank you for this edition. You did a fabulous job. I hope

this gets to a very large audience.” The In Touch/Contact research participants newsletter was created as an action item during the CaNIOS Research Coordinators/Associates meeting in Winnipeg in 2007. We are delighted that patients are very ap-

preciative of this form of KTE. We welcome contributors from other CaNIOS centres. If you want to be part of the summer issue, please contact us at the coordinating centre. Our next issue will come out in July.

## 3 Grant Registrations

Three CaNIOS studies have sent grant renewal

registrations to CIHR. These are GenES,

ThroboFIL and 2000 Faces. Of Lupus research.

## CaNIOS Authorship Definition

To be a named author in any CaNIOS publication, one must meet conditions 1, 2, and 3 below:

- (1) Substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;
- (2) Drafting the article or revising it critically for important intellectual content; and
- (3) Final approval of the version to be published.

## Manuscripts Submitted or Under Revision

### Rheumatology (1000 Faces of Lupus)

Baker K, Pope J, Silverman E, Cooper G, Fortin PR, Zummer M, Smith CD, Petty, R, Tucker L, Albert L, Huber A, Ramsey S, Arbillaga H, Chedéville G, Hudson, M, CaNIOS Investigators; Peschken C. Work Disability in Systemic Lupus Erythematosus is Prevalent and Predicted by Socio-demographic and Disease Related Factors: Results from a Multi-Ethnic Cohort.

### Journal of Rheumatology (1000 Faces of Lupus)

Lalani S, Peschken C, Pope J, CaNIOS 1000 Faces of Lupus Investigators. Clinical Features and Prognosis of Late Onset SLE.

## In Press

### Clinical Medicine: Arthritis and Musculoskeletal Disorders

Law G, Pope J, Lalani S, Silverman E, Cooper G, Fortin PR, Zummer M, Smith CD, Petty R, Tucker L, Albert L, Huber A, Ramsey S, Arbillaga A, Chedéville G, Hudson M, CaNIOS Investigators; Peschken, C. Barriers to Healthcare in a Multiethnic Cohort of Systemic Lupus Erythematosus (SLE) patients: Patient and Physician Perceptions.

### Journal of Rheumatology (1000 Faces of Lupus)

Peschken CA, Katz S, Silverman E, Pope J, Fortin PR, Pineau C, Smith CD, Arbillaga H, Gladman D, Urowitz M, Zummer M, Clarke A, Bernatsky S, Hudson M, Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS). The 1000 Canadian Faces of Lupus: Determinants of Disease Outcome in a Large Multi-Ethnic Cohort .

## Submitted CRA Abstracts

**B-Cell:** Julie Kim, Ellie Aghdassi, Dafna Gladman, Murray Urowitz, Paul R. Fortin, and Joan Wither. Evidence for altered activation of newly-emergent bone marrow-derived B cells in Systemic Lupus Erythematosus (SLE).

**ThomboFIL:** Akhavan PS, Neville C, Su J, Kassis J, Solymoss S, Pineau C, Peschken C, Pope J, Boire G, Rauch J, Fortin PR. Vascular events in systemic lupus erythematosus (SLE): evaluation of thrombophilic factors in a multicentre inception cohort (ThromboFIL).

**LuNNET:** Aghdassi E, Morrison S, Landolt-Marticorena C, Su J, Pineau C, Pope J, Peschken C, Gladman D, Urowitz D, CaNIOS LuNNET Investigators, Wither J, and Fortin PR. Quality of life in lupus patients with and without renal involvement.

**LuNNET:** Adams K, Landolt-Marticorena C, Unnithan T, Gladman D, Urowitz M, Fortin PR, and Wither JE. Circulating levels of sVCAM, IP-10 and MCP-1 correlate with changes in disease activity in Systemic Lupus Erythematosus.

**HIPP:** Aghdassi E, Su J, Claudio J, Morrison S, Cymet A, Neville C, CaNIOS Investigators, Da Costa D, Fortin PR. The Use of Micronutrient Supplements among Patients with Systemic Lupus Erythematosus.

**HIPP:** Al Dhanhani AM, Harvey P, J Su, Cymet A, Harvey P, Da Costa D, Fortin PR. FMD measurement among lupus patients.

**1000 Faces:** Colangelo K, Pope J, Peschken C, and Members of 1000 Faces of Lupus. The minimally important difference for patient reported outcomes in SLE including pain, fatigue and SF36.

**1000 Faces:** Baker K, Pope J, Silverman E, Cooper G, Fortin PR, Zummer M, Smith CD, Petty, R, Tucker L, Albert L, Huber A, Ramsey S, Arbillaga H, Chedéville G, Hudson, M, CaNIOS Investigators; Peschken C. Work Disability in Systemic Lupus Erythematosus is Prevalent and Predicted by Socio-demographic and Disease Related Factors: Results from a Multi-Ethnic Cohort.

**1000 Faces:** Yuen SY, Mok MY, Wong WS, Pope J, Silverman E, Tucker L, Smith CD, Bernatsky S, Pineau C, Zummer M, Chedéville G, Urowitz M, Gladman D, Clarke A, Fortin PE, Peschken C. Systemic Lupus Erythematosus (SLE): A Comparative Study of Clinical Manifestations and Damage in Two Chinese Populations.

## Manuscripts In Preparation (Contact senior author if you wish to be included as author.)

**GenES Study :** Serology Studies - Dr. Joan Wither;  
Environmental Data (i.e., UV light and radiation) - Dr. Glinda Cooper  
Analysis of Candidate Genes and SNPs - Drs. J Wither/Dr. PR Fortin/Dr J Rioux

**LuNNET Study:** BAFF Expression in Lupus - Drs. J Wither/PR Fortin  
Gene expression from renal biopsies - Dr. H. Reich  
Important Predictors of CKD - Dr. Heather Reich/ Paul R. Fortin

**1000 Faces of Lupus Study:** Pediatric Lupus - Dr. L. Tucker/Dr. C Peschken

**1000 Faces of Lupus Study:** The minimally important difference in SLE - Janet Pope

**1000 Faces of Lupus Study:** Predictors and Functional Impact of Lupus Lung Disease—Christine Peschken, Shikha Mittoo

## CaNIOS STUDY ENROLLMENT

### 1000 Faces of Lupus – Enrolled = 1893

Centre 01 MUHC-MGH	297
Centre 04 Maisonneuve Rosemont	90
Centre 07 Ottawa Hospital	85
Centre 08 London	244
Centre 10 Winnipeg HSC	262
Centre 15 Vancouver ARC	22
Centre 17 TWH CPSRD	575
Centre 19 TWH Non-CPSRD	35
Centre 20 Sick Kids, Toronto	145
Centre 21 BC Children's Hosp.	61
Centre 22 Halifax's IWK HC	11
Centre 26 Lethbridge	27
Centre 27 Montreal Child. Hosp.	19
Centre 33 Jewish General Hosp.	22

### HIPP – Randomized = 280

Centre 01 MGH	128
Centre 08 London	47
Centre 17 TWH-CPSRD	89
Centre 19 TWH-Non CPSRD	9
Centre 28 Mt. Sinai & Community	7
<b>GenES Phase I (Recruitment Closed)</b>	
<b>ThromboFIL (Recruitment Closed)</b>	

### LuNNET Cohort 2 (Including 2B and 2C) = 58

Centre 17 TWH CPS	53	Cohort 2	n = 23
Centre 19 TWH non-CPS	4	Cohort 2B	n = 26
Centre 28 Mt. Sinai	1	Cohort 2C	n = 9
<b>Total</b>	<b>58</b>	<b>Total</b>	<b>n = 58</b>

### LuNNET Cohort 3 (Prospective Cohort) = 120

Centre 01 MGH	16	Active SLE with Lupus Nephritis: <b>n = 61</b> Active SLE with out Lupus Nephritis: <b>n = 51</b> In-active SLE with History of Lupus Nephritis: <b>n = 32</b> In-active SLE without History of Lupus Nephritis: <b>n = 27</b> Unknown: <b>n = 5</b>
Centre 08 London	7	
Centre 10 Winnipeg	5	
Centre 17 TWH CPS	88	
Centre 19 TWH non-CPS	4	
<b>Total</b>	<b>120</b>	

### Privacy

If you wish to be unsubscribed from the CaNIOS monthly newsletter e-mail list please contact Jaime O. Claudio, CaNIOS' National S&D Coordinator at:

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## 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. 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.