



# CaNIOS Newsletter



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*Health, Hope, Happiness to Everyone!*

## 1000 Faces of Gingerbread Ladies

The CaNIOS Coordinating Centre at Toronto Western Hospital added new meaning to the catch phrase "1000 Faces". This week, CaNIOS had a successful fundraising event in cooperation with the Arthritis & Autoimmunity Research Centre Foundation (AARCF) at University Health Network. Dubbed Pastry Gram, staff at the coordinating centre baked, packed,



sold, and delivered cookies and banana breads to employ-

ees and visitors at TWH on December 9. Consistent with the theme "Holiday Treats for a Thousand Faces," CaNIOS generated so much interests, including a very special order for gingerbread ladies with diverse faces. Proceeds of our event were donated to the CaNIOS Coordinating Centre.



### Important Dates

**January 15, 2010** - 9th International Congress on SLE Abstract Deadline

**February 3-6, 2010** CRA Conference, Chateau Frontenac, Quebec City

**May 15-16, 2010** - Walk a Block for Lupus

**June 24, 2010** - CaNIOS Business Meeting

**June 24-27, 2010** - 9th International Congress on SLE, Vancouver, BC.

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The new committee chairs have been appointed for 4 CaNIOS Committees. Dr. Christine Peschken is the chair of Scientific & Data Access, Dr. Carol Hitchon is the chair of Authorship & Publication; Dr. Paul Fortin for Fundraising; and Dr. Lori

### CaNIOS Committee Chairs

Tucker and Stephanie Keeling co-chair the new Advocacy & KTE Committee. The Committee chairs were appointed by the Executive for a term of 2 years, renewable thereafter every 2 years. The committee chairs have been inviting members to their respective

committees, and anyone interested to be part of these committees should contact the chairs or the coordinating centre to indicate their interest. Meanwhile, we are looking for a volunteer to Chair the Membership committee.

### Thanks To Our Generous Donors

A private donor from Winnipeg, liaised by one of CaNIOS long-time supporters, the

Funk Family, recently donated to CaNIOS through the AARCF Foundation. Also

recently, Lupus Ontario donated \$5000 from the Walk A Block fund. TYVM to you!

### Travel Subsidy Anyone?

Take advantage of the \$200.00 subsidy from CaNIOS if you are planning to attend the 9th International Congress on SLE in June 2010. The offer is available to all CaNIOS voting

members who will be attending the meeting in Vancouver. So far 5 members have applied for this subsidy. If you are interested, please contact Cathy Chau at the CaNIOS coordinating centre

(cchau@uhnresearch.ca). We only have 5 remaining slots. To qualify, you must be present during the CaNIOS business meeting in the morning of June 24, 2010.

### Disease Cohorts Consortium

During the CAN Annual Scientific Meeting last month the chairs and national coordinators of different rheumatic disease cohorts had an opportunity to meet with Dr. Paul Hebert, the champion for National Strategy on Patient-Oriented Research Initiative, as he shared CIHR's strategic vision for the next 5

years. A panel discussion aptly entitled "Maximizing Research Networks" followed the meeting. This symposium generated a lot of momentum for the disease cohort chairs. As a result, a follow up meeting has been planned in February during the CRA Conference in Quebec City. The goal is to dis-

cuss how to establish a consortium of rheumatology research cohorts in Canada for the purpose of delineating common issues, devising methods of sharing common resources, and advocating for the type of global financial support that is essential for the sustainability of disease networks.



## CRA Abstracts

Morrison S, Aghdassi E, Peeva V, Su J, Landolt-Marticorena C, Gladman DD, Urowitz MB, Pineau C, Pope J, Peschken C, CaNIOS LuNNET Investigators, Wither J, Fortin PR. Perceived Stress in Female Patients with Systemic Lupus Erythematosus (SLE).

Borowoy A, Peschken C, Pope J on behalf of 1000 Faces of Lupus Investigators. The Prevalence of CNS Lupus in Canada: Results from the 1000 Faces of Lupus Cohort.

Lee J, Pope J, Peschken C on behalf of 1000 Faces of Lupus. Incidence of and Predictors of Hospitalization of Patients with Systemic Lupus Erythematosus.

Yip J, Aghdassi E, Su J, Lou W, Reich H, Bargman J, Scholey J, Gladman DD, Urowitz MB, Fortin PR. Serum Albumin as a Marker for Disease Activity in Patients with Systemic Lupus Erythematosus (SLE).

Peeva V, Aghdassi E, Morrison S, Cymet A, Su J, Neville C, Hewitt S, CaNIOS HIPP Investigators, Pineau C, DaCosta D, Pope J, Fortin PF. Cardiovascular Disease Risk Profile in Patients with Systemic Lupus Erythematosus (SLE) without Past History of Cardiovascular Events.

Peeva V, Su J, Aghdassi E, Gladman DD, Urowitz MB, Landolt-Marticorena C, Yeo E, Fortin PR. Clinical Characteristics and quality of life of Patients with primary and secondary antiphospholipid syndrome.

Zhang W, Aghdassi E, Reich HN, Scholey JW, Su J, Lou W, Fortin PR. Impaired Renal Function in Patients with Systemic Lupus Erythematosus (SLE) Predicts Cardiovascular Events.

Zhang W, Aghdassi E, St-Pierre Y, Clarke AE, Landolt-Marticorena C, Morrison S, Su J, Reich H, Scholey J, Herzenberg A, Pineau C, Pope J, Peschken C, CaNIOS Investigators, Wither J, Fortin PR. Health Care Cost in a Canadian Population of Patients With & Without Lupus Nephritis.

Aghdassi E, Peeva V, Morrison S, Cymet A, Su J, Neville C, Hewitt S, Cheung AM, CaNIOS HIPP Investigators, Pineau C, Pope J, DaCosta D, Fortin PR. Low Bone Mass in Female Patients with Systemic Lupus Erythematosus (SLE): A Canadian Study.

Jeyalingam T, Aghdassi E, Su J, Clarke AE, Cooper GS, Rioux JD, Wither J, CaNIOS GenES-Investigators; PR, Fortin. Quality of Life of Patients with Systemic Lupus Erythematosus (SLE) and Their Family Members.

Jeyalingam T., Su J., Brown P.E., Peschken C.A., Pope J.E., Hanly J, Bernatsky S, CaNIOS 1000 Faces Investigators and Fortin PR. Distance to Lupus Centre and Health Care Barriers in Systemic Lupus Erythematosus.

Peschken CA, Pope J, Silverman E, Fortin PR, Pineau C, Zimmer M, Urowitz M, Gladman D, Hudson M, Tucker L, Chevillat G, Huber A, Bernatsky S, Clarke A, Smith CD, Arbillaga H, Ramsey SE, and CaNIOS Investigators. Lupus in Asian Canadians: The 1000 Canadian Faces of Lupus Study.

Bernatsky S, Peschken C, Urowitz M, Gladman D, Clarke AE, Pope J, Fortin PR, Pineau CA, Zimmer M, Smith CD, Arbillaga H, Hudson M and CaNIOS - 1000 Canadian Faces of Lupus. Medication Use in Systemic Lupus Erythematosus.

### 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

#### (LuNNET Cohort I Study)

Reich, HN, Gladman DD, Urowitz MB, Fan CPS, Herzenberg AM, Bargman JM, Cattran DC, Su J, Wither J, Scholey JW, Fortin PR. Chronic kidney disease in systemic lupus erythematosus – more than inflammation. In revision for resubmission.

#### Lupus (1000 Faces of Lupus)

Yuen SY, Mok MY, Wong WS, Silverman ED, Pope JE, Fortin PR, Smith CD, Zummer M, Hudson M, Pineau C, Clarke A, Bernatsky S, Urowitz M, Gladman D, Canadian Network For Improved Outcomes In Systemic Lupus Erythematosus (CaNIOS), Peschken CA. Systemic Lupus Erythematosus: A Comparative Study of Clinical Manifestations and Damage in Two Chinese Populations. Feb 2009.

#### Rheumatology (1000 Faces of Lupus)

Bernatsky S, Peschken C, Fortin PR, Urowitz M, Gladman D, Pope J, Hudson M, Zummer M, Smith D, Arbilla H, Clarke A, CaNIOS. Medication Use in Systemic Lupus.

#### Journal of Rheumatology (LuNNET-TWH)

Zhang W, Aghdassi E, Reich HN, Su J, Lou W, Landolt-Marticorena C, Gladman D, Urowitz MB, Scholey J, Fortin PF. Glomerular Filtration Rate Predicts Cardiovascular Events in Patients with Systemic Lupus Erythematosus. CMAJ.

Yip J, Aghdassi E, Su J, Lou W, Reich HN, Bargman J, Scholey J, Gladman DD, Urowitz MB, Fortin PR. Serum Albumin as a Marker for Disease Activity in Patients with Systemic Lupus Erythematosus.

### In Press

#### Arthritis and Rheumatism

Jung H, Bobba R, Su J, Shariati-Sarabi Z, Gladman D, Urowitz M.B., Lou W, Fortin PR. The Protective Effect of Antimalarial Drug on Thrombovascular Events in Systemic Lupus Erythematosus

#### 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.

Mittoo S, Gelber A, Hitchon C, Silverman ED, Pope JE, Fortin PR, Pineau C, Smith CD, Arbilla H, Gladman D, Urowitz M, Zumer M, Clarke A, Bernatsky S, Hudson M, Tucker L, Petty R, CaNIOS, Peschken CA. Clinical and Serologic Predic-

### Recently Published

#### Journal of Rheumatology (LuNNET and HIPP)

Aghdassi E; Morrison S, Marticorena Landolt C, Su J, Clarke Ann, Gladman D, Urowitz M, Pope J, Peschken C, Pineau C, CaNIOS LuNNET & HIPP Investigators, DaCosta D, Wither J, Fortin PR. The Use of Micronutrient Supplements: Relation to Quality of Life & Disease Activity in Canadian Patients with Systemic Lupus Erythematosus.

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

- GenES Study :** TLR Replication - Dr. Joan Wither  
 Serology Studies - Dr. Joan Wither  
 Environmental Data (i.e., pottery, nail salons, home renovation, etc.) - Dr. Glinda Cooper  
 Analysis of Candidate Genes and SNPs - Drs. J Wither/Dr. PR Fortin/Dr J Rioux  
 Quality of Life - Dr. Paul R. Fortin
- LuNNET Study:** BAFF Expression in Lupus - Drs. J Wither/PR Fortin  
 Gene expression from renal biopsies - Dr. H. Reich  
 Cost Analysis- Dr. Paul R. Fortin
- 1000 Faces of Lupus Study:** Pediatric Lupus - Dr. L.Tucker/Dr. C. Peschken
- HIPP Study:** FMD—Please contact Dr. P. Fortin

## CaNIOS STUDY ENROLLMENT

### 1000 Faces of Lupus – Enrolled = 1979

|                                 |     |
|---------------------------------|-----|
| Centre 01 MUHC-MGH              | 319 |
| Centre 04 Maisonneuve Rosemont  | 105 |
| Centre 07 Ottawa Hospital       | 87  |
| Centre 08 London                | 254 |
| Centre 10 Winnipeg HSC          | 281 |
| Centre 15 Vancouver ARC         | 22  |
| Centre 17 TWH CPSRD             | 575 |
| Centre 19 TWH Non-CPSRD         | 35  |
| Centre 20 Sick Kids, Toronto    | 153 |
| Centre 21 BC Children's Hosp.   | 67  |
| Centre 22 Halifax's IWK HC      | 11  |
| Centre 26 Lethbridge            | 27  |
| Centre 27 Montreal Child. Hosp. | 21  |
| Centre 33 Jewish General Hosp.  | 22  |

### HIPP (Recruitment Closed)

### GenES Phase I (Recruitment Closed)

### ThromboFIL (Recruitment Closed)

### LuNNET Cohort 2 (Including 2B and 2C) = 94

|                       |           |   |
|-----------------------|-----------|---|
| Centre 17 TWH CPS     | 78        | Cohort 2 n = 30<br>Cohort 2B n = 50<br>Cohort 2C n = 11<br>Total n = 91 |
| Centre 19 TWH non-CPS | 14        |   |
| Centre 28 Mt. Sinai   | 2         |   |
| <b>Total</b>          | <b>94</b> |   |

### LuNNET Cohort 3 (Prospective Cohort) = 138

|                       |            |   |
|-----------------------|------------|---|
| Centre 01 MGH         | 24         | Active SLE with Lupus Nephritis: n = 91<br>Active SLE with out Lupus Nephritis: n = 60<br>In-active SLE with History of Lupus Nephritis: n = 53<br>In-active SLE without History of Lupus Nephritis: n = 28 |
| Centre 08 London      | 7          |   |
| Centre 10 Winnipeg    | 5          |   |
| Centre 17 TWH CPS     | 98         |   |
| Centre 19 TWH non-CPS | 4          |   |
| <b>Total</b>          | <b>138</b> | <b>Total: 232</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.